Linking professional organisations of health care to patients' perceptions and experiences of chronic illness. A discussion of health services for type 2 diabetes in Scottish primary care.

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Abstract

UK Health policy over the past decade has sought to accelerate established trends of moving services for type 2 diabetes into primary care. This has aimed to make services more accessible and to enable patients to benefit from having their diabetes care incorporated into the "generic and holistic" approach of primary care. However, in 2004 the introduction of a new General Medical Services (nGMS) contract signalled a change in primary care by linking clinical targets to financial rewards on a larger scale than ever before. Diabetes is one of nineteen financially incentivised clinical areas under the nGMS contract (2006).

This thesis considers how these health policies may have influenced the organisation and experience of providing and receiving care for type 2 diabetes in Scottish primary care settings. It also aims to bridge two usually separate areas of sociological interest: how health professionals interpret and implement policy, and how patients experience and perceive chronic illness and their health care.

A multiple case study approach was employed in order to compare and explore the organisation and experience of type 2 diabetes care associated with three general practices of differing size and location. In each case study a period of non participant observation was undertaken and in-depth interviews conducted with health professionals and their type 2 diabetes patients.

Analysis of these data shows that multiple factors influence the way diabetes care is organised and experienced in primary care. I argue that the local context of inter-personal relationships of trust, professional identities and role expectations influence both the organisation of care and the way patients interpret that organisation. Moreover, the meanings patients attribute to the local organisation of diabetes care can inform their perceptions of their condition and influence their desire to be involved in diabetes management.

Declaration

I, Heather Milne, declare that I have composed this thesis myself, that the work it contains is my own, and that it has not been submitted for any other degree or professional qualification.

Heather Milne

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Abbreviations and Acronyms

DSN: Diabetes Specialist Nurse

OGLA: Oral Glucose Lowering Agent

SMBG: Self Monitoring of Blood Glucose

SIGN: Scottish Intercollegiate Guidelines Network

NICE: National Institute for Health and Clinical Excellence

CHP: Community Health Partnership

MCN: Managed Clinical Network

RCGP: Royal College of General Practitioners

nGMS: new General Medical Services Contract

QOF: Quality and Outcomes Framework

Hypo: Hypoglycaemia

NHS: National Health Service

GP: General Practitioner

DESMOND: Diabetes Education and Self Management for Ongoing and Newly Diagnosed

QIS: Quality Improvement Scotland

UKPDS: United Kingdom Prospective Diabetes Study

SIMD: Scottish Index of Multiple Deprivation

Chapter 1: Background to the research

Introduction

This thesis is about providing and receiving care for type 2 diabetes in primary care settings in Scotland. In it I will explore the ways in which health policies directed at type 2 diabetes care are interpreted and implemented in differing primary care settings and how this might shape patients' experiences and perceptions of their condition. In doing this, the thesis links two areas of previous research which have focused on the organisation of health care, and the experience of living with and managing type 2 diabetes.

There are several reasons why this is a particularly salient area for research. Firstly, Scotland has been described as being in the "grip of a diabetes epidemic" (Moss, 2009). In 2008 the prevalence of known diabetes in Scotland was 219,963 people, 4.3% of the population. 86.7% of these cases were type 2 diabetes and the incidence is fast increasing (Scottish Diabetes Survey Monitoring Group, 2008). This is associated with the ageing population and rising numbers of people being overweight (Scottish Diabetes Survey Monitoring Group, 2008).

Diabetes is associated with the risk of various macro and micro vascular complications, including: heart attacks, stroke, peripheral vascular disease, neuropathy (a loss of sensation in hands and feet), nephropathy (kidney disease) and retinopathy (causing reduced vision) (Scottish Diabetes Survey Monitoring Group, 2008). Tight control of blood glucose and blood pressure reduces the risk of these complications and has been presented as the best way to reduce the high cost of their treatment in the NHS (Bramley-Harker et al., 2005; UK Prospective Diabetes Study Group, 1998a; 1998b; 2000). However, achieving tight control of blood pressure and blood glucose is reliant on patients adopting regimens of diet and exercise alongside pharmaceutical interventions. Patients' adoption of such regimens has been shown to be influenced by various factors including the experience of physical 'symptoms', social, cultural and

economic barriers and facilitators, and their overall perception of their condition (Drummond and Mason, 1990; Hepworth, 1999; Hunt et al., 1998; Lawton et al., 2005a; Murphy and Kinmonth, 1995). In addition, Lawton et al. (2005b) have shown that the organisation of diabetes services may influence patients' perceptions of type 2 diabetes. Hence, a greater understanding of how health services for type 2 diabetes are being organised and the significance of this for patients' perceptions of their condition has the potential to inform the development of health care services.

The second reason this research is particularly salient, is that the organisation of both general practice and health services for diabetes have been changing. In parallel with policy for many other long term conditions, Scottish health policy over the past nine years or so has accelerated established trends of moving type 2 diabetes services out of secondary care and into primary care. In addition, the introduction of a new General Medical Services (nGMS) contract in 2004 represents a significant change in British general practice (which provides the majority of primary care). However, how these changes are influencing the organisation of diabetes care in primary care and the implications of this for patients' perceptions and experience of their condition remain poorly understood and will be explored in this thesis.

In this introduction I will set the scene for the thesis by outlining some of the biomedical background to type 2 diabetes and the health policies influencing its care. I will then go on to outline the approach of the research presented here and the topics covered within each chapter of the thesis.

Background

Diabetes Mellitus

Diabetes mellitus is a medical condition characterised by the body's inability to lower the level of glucose (sugar) in the blood. This is attributed to the reduced production and/or effectiveness of the hormone insulin which, in a 'healthy' person, would reduce levels of blood glucose. Type 2 diabetes was first clearly differentiated from type 1

diabetes in the 1930s (Black and Gray, 1995). The biomedical criteria for the diagnosis and classification of type 2 diabetes have shifted over its history; for example, with the introduction of new diagnostic criteria by the World Health Organisation (WHO) in 1999; hence the particular population considered to have diabetes has also changed over time (DECODE Study Group, 1998). So, the definition and the criteria for diagnosis of type 2 diabetes are both partly the product of the social and historical context.

Type 2 diabetes is currently diagnosed when blood glucose concentrations exceed a certain threshold following a fasting blood glucose or an oral glucose tolerance test (Williams and Pickup, 2004). The threshold value is based on epidemiological studies demonstrating associations between these blood glucose levels and the eventual development of the diabetes specific microvascular complications of retinopathy and nephropathy (Williams and Pickup, 2004). In 1999, previous classifications of the disease on the basis of its clinical management with insulin were replaced by the World Health Organisation (WHO) with classifications of type 1 and type 2 diabetes based on understandings of the aetiology of the disease[1]. The focus of this study is the more prevalent, type 2 diabetes, which I will, for the sake of brevity, sometimes refer to simply as "diabetes".

Biomedically, the onset of type 2 diabetes is thought to be caused by a combination of genetic and "environmental" factors which include a sedentary lifestyle, being overweight and ageing (Williams and Pickup, 2004). Whilst the exact aetiology is not completely understood these factors lead to a variable combination of decreased insulin production and a reduction in its effectiveness, commonly termed "insulin resistance" (Williams and Pickup, 2004). Following the results of the United Kingdom Prospective Diabetes Study (UKPDS) in 1998, the management of type 2 diabetes has been shown to require both blood pressure and blood glucose control in order to avoid the disease's

[1] There are also other less common classifications of diabetes, for example those caused by the side effects of drugs or gestational diabetes.

complications (UK Prospective Diabetes Study Group, 1998). Ongoing blood glucose control is usually assessed by measuring the percentage of glycated haemoglobin (HbA_{1c}) in the blood. This gives an indication of blood glucose control over the preceding two to three months (Williams and Pickup, 2004). Current Scottish clinical guidelines set the HbA_{1c} target at $\leq 7\%$[2] (Scottish Intercollegiate Guidelines Network, 2001).

The approach to achieving glycaemic control for each patient varies. It is dependent on the clinician's judgement of the disease's progression and the "likely balance" between insulin resistance and loss of insulin production (Pickup and Williams, 2004: 111). Often patients will begin by managing their diabetes through diet and exercise alone, but this only achieves initial glycaemic control in about 10-20% of people (Pickup and Williams, 2004). Hence, people with type 2 diabetes are likely to go onto one or a combination of a variety of tablets (oral glucose lowering agents) and/or insulin. Fifty percent of people with type 2 diabetes then need to use insulin injections within 6 years of diagnosis (Pickup and Williams, 2004).

However, achieving tight glycaemic control through the use of insulin and some oral glucose lowering agents is associated with an increased incidence of iatrogenic hypoglycaemia (UK Prospective Diabetes Study Group, 1998a). In hypoglycaemia blood sugars fall too low to provide energy to the brain which can, but does not always, lead to symptoms such as dizziness, sweating, nausea, and eventually can cause a loss of consciousness and death (Williams and Pickup, 2004). All insulins are associated with the risk of hypoglycaemia; however, not all oral glucose lowering drugs are equally likely to cause hypoglycaemia. For example, Metformin, which is a common first line

[2] The National Institute for Health and Clinical Excellence (NICE) upgraded their guidelines on disease management to a target HbA1c of ≤6.5% in 2008. However, there is concern over trying to achieve such tight blood glucose control after clinical trials (ACCORD Study Group, 2008) showed a higher mortality rate for intensively managed patients. SIGN will be reviewing their guidelines in 2009. The lowest target rewarded in the Quality and Outcomes Framework (QOF) for 2010 remains ≤ 7%.

treatment, is associated with side effects such as diarrhoea but is not usually associated with hypoglycaemia as it does not prompt the body to produce more insulin. In contrast sulphonylureas such as Gliclazide prompt the cells in the pancreas to produce more insulin and hence are associated with both weight gain and hypoglycaemia (Williams and Pickup, 2004).

This background to the condition and its management, including the side-effects of drugs, informed my understanding of patients' accounts of what it is to live with and receive care for type 2 diabetes presented in this thesis. However, it is my intention that my analysis should not be limited by the current biomedical definition of the disease, which negates the social and experiential aspects of living with diabetes. In the next section I will outline some of the historical health policy background to type 2 diabetes care in order to situate my analysis of the service organisations described in the thesis within their own social and historical context.

Diabetes care in Scotland

Historically, diabetes care in the UK has been the preserve of secondary care because of its history as an illness leading to high rates of mortality and involving complex regimens of care. As distinctions between what are now known as type 1 and type 2 diabetes were not proposed until the 1930s, both types of the condition were originally managed in secondary care (Black and Gray, 1995). The prescription of insulin as a potent and dangerous drug has also typically been the jurisdiction of secondary care, and even now with much more simplified regimens and safer insulin, many primary care professionals remain hesitant to prescribe it (Baxter et al., 2006; Scotsman Digital Archive, 1923).

Proposals for sharing care for diabetes between hospital and the community were not made until 1953 but there was little change until the 1970s (Griffin and Kinmonth, 1998). Indeed, the involvement of general practitioners remained sporadic until the 1990s when GPs started to take responsibility for predominantly uncomplicated patients not using insulin (Griffin and Kinmonth, 1998). This was partly in response to

government financial incentives for GPs to run chronic illness clinics and the introduction of the "fundholding" policy, a program through which GPs could choose to become purchasers of hospital services (Pollock, 2005). These policies made it more financially attractive to provide diabetes care in general practice. The role of practice nurses also developed over this period and they also started to become more involved in chronic illness management (Griffin and Kinmonth, 1998).

As part of the New Labour government's policy of "clinical governance" in 2001/2002, each of the countries of the UK published a National Service Framework for diabetes. In Scotland this took the form of the Scottish Diabetes Framework (SDF). The framework aims to promote evidence-based and "equitable care" for diabetes across Scotland. It draws on evidence for clinical care collected and summarised in guidelines produced by the Scottish Intercollegiate Guidelines Network (SIGN) and the National Institute for Health and Clinical Excellence (NICE). Alongside this, the SDF aims to encourage "patient-focused care", "empowering" people with diabetes to "manage their own care" (Scottish Executive, 2002, 25).

White papers such as *Partnership for Care* (2003) and *Delivering for Health* (2005) claimed that primary care was the best setting for delivering diabetes care for two reasons: firstly, as primary care centres (usually GP surgeries) tend to be situated within the patient's community they are more convenient for patients to access than secondary care; secondly, that the "generic and holistic approach" of primary care is well suited to managing chronic illnesses and multiple conditions (Scottish Executive, 2003, 36). Providing diabetes services in primary care has also been shown to be more cost effective than secondary care, which must be an important concern for policy makers given the increasing prevalence and the high cost of diabetes to the NHS (Bramley-Harker et al., 2005).

The approach to organising diabetes services in Scotland has emphasised cooperation. For example, the development of Managed Clinical Networks (MCNs) in each Health Board was intended to support the organisation of care across professional boundaries

and, hence, support the move of services into primary care (Scottish Executive, 2002; 2003). Moreover, the shift of 'uncomplicated' diabetes services into primary care has been consolidated by the introduction of a new General Medical Services (nGMS) contract for primary care providers in 2004. In 2007 88% of Scottish general practices were employed through the nGMS contract, and most practices employed through other contract options have also taken part in the nGMS contract's Quality and Outcomes Framework (Audit Scotland, 2008). The Quality and Outcomes Framework (QOF), is an optional set of financially incentivised targets in the domains of performance in clinical services, organisation, patient experience and additional services (Department of Health, 2003). Up to 25% of the practices' possible income has been linked to these targets and few practices have opted not to take part (Guthrie et al., 2006). Diabetes has been one of the financially incentivised clinical areas of the QOF since its introduction. Practices are rewarded for processes which, in 2006, included: maintaining a register of all patients with diabetes, and recording whether patients had had blood pressure, cholesterol, HbA_{1c} and kidney function measured, peripheral pulses checked, and retina screened within the past 15 months. Further points were also rewarded for the percentage of patients meeting targets in intermediary outcomes such as having an HbA_{1c} of 7.5% or less and a blood pressure of 145/85 or less (BMA and NHS Employers, 2006). So, with the implementation of QOF one might expect increased standardisation in the organisation and provision of care for diabetes. Indeed, as I will discuss further in the next chapter, the contract has already been shown to have furthered the trend of practices establishing nurse-led chronic illness clinics (Roland et al., 2006).

The clinical targets incorporated into QOF are based on the same evidence underpinning the SIGN clinical guidelines, the Scottish Diabetes Framework (Scottish Executive, 2002) and the clinical guidelines produced by NICE. However, the QOF does not reward the less easily measured aspects of providing a personal and holistic service (Scottish Executive, 2003), nor does the QOF necessarily promote policy ideals of collaboration. Indeed, as observed by Kenny (2005), the contract ignores the patient-focused elements such as information, education, and empowerment in the national service frameworks.

Hence, it may bias care more towards pharmaceutical intervention and measurable outcomes (Kenny, 2005).

Finally, it should be highlighted that patients may also receive diabetes care from community podiatrists, dieticians, and psychologists who may or may not be based at their general practice (Diabetes UK, 2001). Moreover, since the 1950s there have been health visitors providing diabetes care, who were later known as Diabetes Specialist Nurses (DSNs) liaising between the hospital clinic and the community, visiting patients in their homes and adjusting insulin regimes (Grzebalski, 1998). Since the 1980s the number of DSNs has burgeoned and they continue to provide care to patients (particularly those using insulin), often organise structured patient education in the community, and act as a source of information and education for other primary care professionals (Grzebalski, 1998; James et al., 2009). However, since 2000 there has been a pattern of DSNs being based either in hospital or the community, hence threatening their traditional role working across both primary and secondary care (James et al., 2009, 563).

The organisations of diabetes care presented in this thesis are understood within the context of the historical organisation of care which has involved negotiations of labour in diabetes services, particularly between the primary and secondary care sectors. In particular, the way in which the Scottish Diabetes Framework and other policy initiatives and instruments (such as MCNs and QOF) have influenced how care is provided to patients in general practice is a central concern of this study.

Aims and objectives

This thesis aims to further the understanding of how health policy might influence the organisation of care for type 2 diabetes in primary care, and the significance of that organisation for patients' experiences and perceptions of their condition. This can be broken down into two overlapping objectives. The first objective is to understand how policies relating to diabetes care are being interpreted and implemented by health

professionals in primary care settings. The second is to explore how the resulting organisation of care is experienced and interpreted by patients, and whether this informs their perception and experience of living with type 2 diabetes. To meet these objectives this thesis draws on a multiple case study analysis of three primary care diabetes services and patients' experiences of these.

Thesis outline

The presentation of this research is divided into seven chapters. In chapter two I will situate the research alongside established literature on the organisation of health care and general practice, and patients' experience of chronic illness and type 2 diabetes. I will demonstrate how my research questions were developed to address a particular lacuna in previous research. I will then go on in chapter three to outline and present a rationale for the research design, and describe the sample recruited and the process of carrying out the case studies. In this chapter I will also highlight some of the difficulties and quandaries I faced when collecting the data.

In chapters four to eight I will present my empirical findings. Chapter four will introduce the general practices in each case study and the organisation of diabetes care at each. It will highlight the similarities and differences in the organisation and approach to diabetes care and suggest that this might be related to the ethos of the practice as a whole. Chapter five goes on to consider the organisation of diabetes care in each case study in more detail. In this chapter I will consider the factors influencing which professionals were involved in diabetes care, both within and outwith the practice, and the factors shaping local patterns of referral. I will argue that interpretations of health policy and the organisation of diabetes care are shaped by the local and historical context and specifically, professional identities and inter-professional relationships.

In chapter six I turn to the second research objective and examine and explore the ways in which patients' experience and assessment of their diabetes care is related to their perceptions of their general practice and their previous experiences of receiving

competent care. It will also discuss the extent to which patients perceived their diabetes services to be holistically incorporated into their generic general practice care, and whether they viewed this as facilitating 'good care'. Chapter seven then goes on to show that patients' assessments of their professionals' expertise are locally constructed. Hence, the meanings patients attribute to being referred from one professional to another which, under some circumstances may be interpreted as an external indicator of the state of their condition, are locally contingent.

Chapter eight uses the example of "patient empowerment" in order to demonstrate how the local interpretation of the policy goal of patient involvement in clinical decisions is mediated through professionals' perceptions of their own role in diabetes care. Moreover, I will argue that this in turn influences patients' own perceptions and desire for involvement in clinical decisions, so illustrating how the local context of care can shape patients' own experience and desire to be included in decisions about their diabetes.

Finally, chapter nine draws together the various findings of the thesis and discusses three factors which emerge as particularly salient in shaping both professionals' organisation of diabetes care and patients' interpretations of that organisation. I will then reflect on the strengths and weaknesses of my research design and suggest some avenues for future research before concluding the thesis by highlighting my contributions to existing knowledge.

Chapter 2: Moving from policy to patient, a literature review

Introduction

This literature review is divided into two parts reflecting two areas of academic concern and the gap between them, which this thesis aims to bridge. The first part focuses on how instruments of recent UK health policy have been considered to influence the organisation and provision of everyday clinical services, specifically in general practice and in relation to type 2 diabetes care. It will then go on to consider how differing organisations of health services and professionals' preconceptions of a disease may influence clinical decisions and, hence, the care patients receive.

The second part of the literature review will outline what we already know about patients' experiences and perceptions of type 2 diabetes. Whilst not all this research has been developed within sociology, it sits alongside the sociology of chronic illness, and like the majority of work in this field, has focused on people's experiences and understandings of illness within the context of their wider lives, rather than on their interaction with, and interpretation of, health services. Only a few studies have suggested that interactions with health services should also be considered significant influences on living with chronic illness (Hart, 2001) and on people's perceptions of their condition (Lawton et al., 2005a). Hence, I will suggest that if we are to better understand patients' experiences of type 2 diabetes, we need to consider the influence of the health care they receive as part of their lives with the condition. However, as mentioned above, health care is being shaped by the various changes in policy and the health professions. Hence, this review will argue that furthering links across these two fields of research, as this thesis aims to do, will provide a more complete understanding of how health policy may influence patients' experiences and perceptions of diabetes.

Influences on the organisation and provision of services for type 2 diabetes in British primary care

The introduction of new modes of organisational governance in healthcare systems have had a "profound impact on the social organisation of work" (Allen and Pilnick, 2005, 683). This has included shifts within the division of labour between health professionals, changes to working practices, and in some cases has been viewed as an attack on professional autonomy (Allen and Pilnick, 2005). In line with these observations, the ways in which the policy instruments, associated with New Labour's policy of 'clinical governance', influence the micro-level of organising services in primary care forms the first focus of this review. The Scottish Diabetes Framework (Scottish Executive, 2002) and the new General Medical Services contract (Department of Health, 2003), discussed in the introductory chapter, employ policy instruments, such as evidence-based clinical guidelines and standardised clinical targets, to try and achieve the provision of high quality and equitable care for diabetes in general practice. However, policy instruments are not purely technical but "produce specific effects, independent of their stated objectives" (Lascoumes and Le Gales, 2007, 10). The unanticipated effects on the organisation and delivery of care for diabetes are a key consideration of this research.

Policy instruments, clinical autonomy and professional divisions of labour

According to Harrison and Ahmad, we are witnessing the emergence of what they term "scientific-bureaucratic medicine":

> Scientific in the sense that its prescriptions for treatment are drawn from an externally-generated body of research knowledge, and 'bureaucratic' in the sense that it is implemented through bureaucratic rules, namely, clinical guidelines. (Harrison and Ahmad, 2000, 138).

Harrison and Ahmad (2000) argue that this threatens professional autonomy both in its relationship with the state, but most significantly for the concerns of this research, at the micro-level of everyday clinical practice. Others highlight that guidelines and practices of audit established within the medical profession originally acted to further professional authority through their appeal to the scientific basis of practice (Power, 1997;

Timmermans and Berg, 2003). However, once co-opted by the state, they became instruments of governance acting to discipline the clinical practice of the professions (Timmermans and Berg, 2003).

Drawing on Foucault's notions of power, Flynn (2004) cogently argues that clinical governance is "a particular form of governmentality". Governmentality is a notion defined by Foucault as a form of government which uses institutions and procedures of surveillance as tactics to control the behaviour of populations (Foucault, 1978, 221). Governmentality is an exercise of a productive form of power which is dispersed within the social system and regulates the population around particular norms of practice in such a way that the population becomes self-regulating (Foucault, 1978). Hence, Flynn suggests that, through the use of guidelines and external audit as part of clinical governance, clinicians have become self-auditing, aligning their goals with the external targets set by a tier of non-clinical management (Flynn: 2004: 20). Flynn (2004) argues that clinical governance is a strategy through which the nature of medical knowledge and practice is being shifted. It is changing from being "embrained" and "embodied" knowledge which is tacit and based on extensive learning and individual experience, to being "encoded" knowledge which is explicit and codified, common in organisations which emphasise "managerially generated rules, monitoring procedures and performance standards" (Flynn, 2004, 23) (see also, Nettleton et al., 2008). According to Flynn (2004), professional practice is changing, bringing it increasingly under managerial control as in Lam's (2000) model of a "machine bureaucracy".

Abbott (1988) argues that by changing the nature of professional work, the relationships between the professions themselves are altered. Hence, which professionals provide diabetes care in primary care may also change in response to policy initiatives if they are perceived to change the nature of the tasks involved. Abbott (1988) theorises that professions exist in an inter-dependent system, where each profession defines its jurisdiction through its idiosyncratic knowledge applied to particular areas of work. Hence, if external forces create, abolish or reshape the nature of the work undertaken by a profession, then this in turn affects the relationship between professions in the system.

Abbott suggests that the extent to which tasks might become routine, and hence not seeming to require specialist knowledge, is particularly salient in changing the relationship between professions:

> In every case, the eventual result has been the degradation of what had been professional work to nonprofessional status, sometimes accompanied by the degradation of those who do the work (Abbott, 1988, 125-126).

Abbott (1988) asserts that if a profession is to survive, it must maintain its specialised niche. Hence, as the increased use of guidelines and protocols transforms the nature of the knowledge required, by making it less dependent on 'professional judgement', those areas affected become potentially degrading for the profession, and are either open for poaching by other professions, or are delegated to a subordinate profession (Abbott: 1988). So, if the tasks of diabetes care are perceived to have become routine, one might hypothesise that there will be a shift in which professionals deliver that care to patients.

Finally, Byrne (2004) and May et al. (2006) argue that the protocols and guidelines used as the basis for audit under 'clinical governance' negate the multiple aspects of knowledge incorporated into clinical decision making; for example, knowledge of the patient's social situation. The kind of information which is recognised as valid in the clinical encounter is apparently being altered. Supposing that clinical care can follow a rational series of decisions in the manner of a protocol or guideline makes some aspects of clinical work explicit whilst obscuring others, usually those aspects of work which are not easily quantifiable (Berg, 1997; Lambert, 2006; Strathern, 2000).

Moreover, May et al. (2006) have argued that the parallel pursuit of evidence-based practice and patient-centred care (the twin bases of the Scottish Diabetes Framework) "are about more than clinical autonomy and managerialism", as they "also represent struggles over what kinds of experiences and knowledge patients are authorised to bring to the clinical encounter, and how these are made to count" (May et al., 2006). Hence, May et al. suggest that, acting together, the products of evidence-based and patient-centred medicine constitute a new form of Foucauldian governmentality. They not only

limit the clinical autonomy of the professionals, but also, produce particular forms of subjectivity in both patients and professionals by legitimising particular forms of knowledge over others (May et al., 2006). So, one might expect these policy initiatives to not only influence the practice of clinicians, but also the way in which patients are encouraged to present themselves and their illness in the clinical encounter. This is also suggested by discussions of the influence of policies of "patient empowerment".

"Patient empowerment" and "street-level bureaucrats"

In the Scottish Diabetes Framework (Scottish Executive, 2002) "patient empowerment" is presented as involving two aspects. Firstly, it recognises that the person with diabetes is the main actor in managing their condition. Secondly, patients are intended to have a more egalitarian 'partnership' relationship with health care providers and to contribute to 'treatment' decisions based on their own expertise of how regimens of self-care might best fit into their lives. These aspects generally reflect the academic understandings of 'empowerment' (Funnell and Anderson, 2004; 2000; Paterson, 2001a). They also fit into the broader and well established idiom of patient-centred care first posited by Byrne and Long (1976) (Mead and Bower, 2000). However, research into patients' experiences of involvement in treatment decisions indicates that these ideals are rarely actually achieved (Bissell et al., 2004; Paterson, 2001a). Paterson (2001a) suggests that this is because, despite espousing a rhetoric of patient empowerment, professionals continue to position themselves as the sole authority in clinical decisions rather than adopting practices to enable patient empowerment. Furthermore, Paterson (2001a) points out that a lack of time in the clinical encounter can be a limiting factor in empowerment.

Similarly, Montori et al. (2006) theorise that establishing therapeutic partnerships may be difficult if the health service organisation does not facilitate appointments of adequate length or frequency. Equally, they suggest that:

> Clinical practice guidelines coupled with quality audits and a system of penalties and incentives may push clinicians to 'ensure' that patients decide to use and adhere to 'best' therapies" (Montori et al., 2006, 34).

Hence, according to Montori et al. (2006), patient-centred care may be undermined by the instruments of 'clinical governance'. Others theorise that "empowerment" is a rhetoric employed to maintain medicine's authority in the face of the impossibility of curing chronic illness (Salmon and Hall, 2003). By handing over responsibility for the disease to the patient, professionals release themselves from the inevitable failure of managing a disease they cannot cure; professional authority is maintained by claiming to enable "empowerment" (Salmon and Hall, 2003). Similarly, on the basis of semi-structured interviews with eighty GPs Armstrong (2002), argues that the discourse of 'patient-centred care' is as a defence against the potential threat to professional autonomy posed by clinical guidelines. Their autonomy is maintained through claims to have the specialised knowledge required to apply generic evidence-based guidelines to the individual needs of each patient. So, Armstrong's (2002) study suggests that even when clinical guidelines had been introduced, the care patients actually receive may continue to depend on the discretion of their GP. This contrasts with the literature in the previous section which suggested that policy instruments such as clinical guidelines were undermining doctors' professional autonomy in general. Armstrong's (2002) findings show continuing variation between individual clinicians in clinical practice rather than the standardisation which would be associated with strict adherence to guidelines.

Similarly, based on three general practice case studies, Checkland (2004) demonstrates that GPs maintain their clinical autonomy through the selective use of clinical guidelines and implementation of National Service Frameworks (NSFs). She suggests that GPs act as "street-level bureaucrats", a notion borrowed from Lipsky (1980), who defines these as "public service workers who interact directly with citizens in the course of their jobs, and who have substantial discretion in the execution of their work" (Lipsky 1980: 3). Lipsky (1980: 13) argues that policy is not simply the written document produced by the government. Rather, he presents policy as created through the everyday discretionary actions of street-level bureaucrats and their relative autonomy in making decisions about the applicability of various rules and regulations to individual members of the public

(Lipsky, 1980). So, for example, a GP may choose not to apply a certain aspect of a guideline to the care of a particular patient because these conflict with his/her notions of best care, or because the document appears too complex to be easily applied to the practical needs of everyday service provision (Checkland, 2004).

Similarly, in their ethnographic study of the use of guidelines in two general practices Gabbay and le May (2004) found that practitioners did not use guidelines in the manner suggested by liner-rational models of evidence based healthcare. Instead professionals acquired what they thought would be the best evidence base "from sources they trusted". (Gabbay and le May, 2004, 1015). The clinicians relied on what Gabbay and le May term "mindlines", these are:

> Collectively reinforced, internalised tacit guidelines, which were informed by brief reading, but mainly by their interactions with each other and with opinion leaders, patients and pharmaceutical representatives (Gabbay and le May, 2004, 1015).

The development and internalisation of these "mindlines" were mediated by trust in their colleagues. They also observe that they were shaped by other factors such as:

> The organisational features of the practice, such as the nature and frequency of meetings, the practice ethos, and its financial and structural features, including the computer system (Gabbay and le May, 2004).

Hence, whilst the considerations of professional identity and associated divisions of labour outlined in the previous section are important, other factors may impact on the way guidelines are used in everyday practice. Particularly significant considerations seem to be inter-professional communication and trust and the organisational features of a general practice which facilitate this. It seems, according to Gabbay and le May (2004), that guidelines do not necessarily lead to the codification of professional knowledge but are incorporated into tacitly held knowledge within a "community of practice" (Wenger, 1998 as cited by Gabbay and le May, 2004). However, both Checkland's (2004) and Gabbay and le May's (2004) studies were carried out before the nGMS contract was fully implemented, which, with its financially incentivised goals,

possibly leaves less room for the exercise of individual discretion (despite the option of exception reporting[3] some patients).

In addition to considering the discretion of individual practitioners to differentially apply guidelines to individual cases, it is also worth considering how the local context of social relationships in which a policy is implemented affects the meanings attributed to it and how it may therefore have unexpected consequences (Shore and Wright, 1997). Interpretative approaches to policy analysis (Wagenaar and Cook, 2003; Yanow, 1993; Yanow, 2007) focus on the meanings and interpretations informing both the writing and implementation of policy within their specific social and historical contexts. Like Lipsky's (1980) theory of street-level bureaucrats, this approach views policy as the product of the everyday deliberations and actions of those involved which are based within a particular situated context (Wagenaar and Cook, 2003). Policy documents, policy instruments (such as clinical guidelines), and artefacts (such as a building) are attributed meanings by the different 'communities' they relate to (Yanow, 2003). Hence, understanding local interpretations are essential to understanding the way in which policy goals and instruments are ultimately enacted and reacted to (Yanow, 1993; Yanow, 2003).

Policy documents themselves may be used as tools to further one group's agenda over that of another in inter-professional relationships (Hansen, 1997). In Hansen's ethnography of doctor-nurse-patient interactions on a hospital oncology ward, he draws on Bourdieu's (1990, as cited by Hansen, 1997) theory of symbolic capital to argue that

[3] Under the new GMS contract quality and outcomes framework (QOF) practices are financially rewarded for carrying out particular tasks and for patients meeting set clinical targets. However, for various reasons outwith their control, practices may not be able to carry out these tasks or reach clinical targets for particular patients. When this is the case, a patient may be 'exception reported' excluding them from the calculation of the practice's QOF achievement. Situations under which a patient may be exception reported include but are not limited to: if they refuse to attend review appointments and have been invited three times in the previous 12 months; if it is inappropriate for them to attend due to particular circumstances such as being terminally ill; if they have newly joined the practice; if they refuse a medication or are already on maximum tolerated doses or for some other reason it is clinically inappropriate to prescribe more (General Practitioners Committee, 2004).

the differing professional groups used the symbolically high status and authority of a written hospital policy document to further their own agenda in patient care (Hansen, 1997). In this case the hospital policy document is used as a source of power and authority to further the interests of one actor over another.

Similarly, representations of care pathways by differing professionals reveal intrinsic assumptions about the roles each professional group views themselves as having. Pinder et al. (2005) found that the differing professionals involved in care for cataracts presented the care pathway in quite differing ways, tending to place their own professional involvement as central and excluding or sidelining some of the other professionals involved. They similarly occluded the role of the patient's friends and family in providing essential aspects of care outwith the official health care system, and other factors informing when a patient might use the system. Hence, as these pathways represent systems of referral, who a patient meets over the course of receiving care may be influenced by the perspective of individual professionals.

What these studies highlight is that the implementation of policy instruments such as clinical guidelines can be mediated by the context of the organisation and the variable professional relationships involved in providing care. As policies aim for type 2 diabetes care to be provided in primary care, general practice organisations form the context of policy interpretation and may influence its implementation. This thesis will aim to investigate whether this is in fact the case, particularly as there has long been much variation in British general practice, as I will now go on to discuss.

British General Practice

Through the defining work of thinkers such as Balint (1957), general practice has, from the 1950s onwards, defined its approach to medicine in contrast to hospital medicine, leading to the articulation of "core values" (Armstrong, 1979; Bosanquet and Salisbury, 1998). These include: "continuity of care", holistic care or "understanding the social context of patients' problems, formulating diagnoses in physical, social and

psychological terms" and a role in promoting public health (Bosanquet and Salisbury, 1998, 52).

However, understandings of holism and continuity vary across the general practice literature. Originally taken to mean understanding the patient and their illness in their social environment, holistic care, has come to be defined in multiple ways (Checkland et al., 2008; Lawrence and Weisz, 1998). For some, holistic care has become largely synonymous with Engel's (1977) proposal for a biopsychosocial model of medicine. Engel (1977) argued that the dominant biomedical model provided only an incomplete understanding of disease if the patient's social context and psychology were not also considered. However, some have also conflated holism with the notion of "patient-centred" medicine, meaning taking into account the patient's concerns within the consultation context (Checkland et al., 2008). The World Organisation of Family Doctors (WONCA[4]) defines holistic care as "a biopsychosocial model taking into account cultural and existential dimensions" (WONCA EUROPE, 2005, 22).

Continuity of care has equally been understood in multiple ways. Freeman et al. (2003) identified six elements of continuity of care derived from a literature review of the concept across all medical disciplines: patients' experienced continuity, informational, cross-boundary, flexible, longitudinal and relational continuity. From these Freeman et al. (2003) suggest that the latter two which involve seeing the same professional or professionals over time, and the development of a therapeutic, interpersonal relationship contribute most to traditional definitions of general practice.

In order to avoid confusion, I will refer in this thesis to 'co-ordination of care', and 'relational continuity'. By 'coordination' I mean both "the common thread linking care from one provider to another", the transfer of information focused on either the person

[4] The acronym WONCA is derived from the first five initials of the full title of this organisation, which is "**W**orld **O**rganization of **N**ational **C**olleges, **A**cademies and Academic Associations of General Practitioners/Family Physicians."

or their disease and, when the services provided by the multiple health professionals involved are "delivered in a complementary and timely manner" (Haggerty et al., 2003, 1220). These are what Haggerty terms "informational" and "management" continuity, which seem to be equivalent to Freeman et al.'s definitions of "informational" and "cross-boundary" continuity (2003, 264).

By 'relational continuity' I mean the ongoing interpersonal relationship between health care professional and patient. Relational continuity is thought to be of particular importance in the development of trust, empathy and respect, and to facilitate professionals in making a "multidimensional diagnosis, based on the biopsychosocial model within the patient's context" (Freeman et al., 2003, 264), i.e. relational continuity may enable holistic care. As I will go on to discuss, this form of continuity has been identified as particularly important to patients with type 2 diabetes (Alazri et al., 2006), and is presented by health policy as a justification of providing diabetes care in general practice.

Finally, the role of general practice in promoting public health is exemplified in the well-known work of the GP, Tudor-Hart who studied and promoted the health of his patient population alongside writing highly influential academic works such as the "inverse care law" (Huby et al., 2008; Tudor-Hart, 1971, 2009). The new General Medical Services contract can also be viewed as the most recent of various attempts to promote general practice's role in public health (Peckham and Hann, 2008). Alongside continuity of care, holism and public health, which continue to be used to define general practice, Gillies et al.'s (2009) recent attempts to distil the "essence of general practice" have suggested that a definition of the discipline should also include: a concern with trust, patient-centred care and good communication within the consultation. In addition, team working, coordinated care, generalism and providing care for chronic illness were also identified as key future roles for GPs (Gillies et al., 2009).

As is perhaps implied by the breadth of conceptualisations of the defining features of the field, British general practice is diverse, indeed Helman (2002) has commented that:

> A key characteristic of general practice is its enormous diversity. Each practice has — to some extent — its own sub-culture: its own unique assumptions, expectations, behaviour patterns, attitudes to patients, internal organisation, use of space and time, and ways of delivering health care (Helman, 2002, 619).

This variation has been described and explained along various lines including: the practice's location (for example, in an urban or rural, affluent of deprived area), the population it serves, its size, and the ethos espoused by the health professionals.

Location and size

Over twenty years ago, Horobin and McIntosh (1983) highlighted significant differences between urban and rural general practitioner's approaches to the use of time and access to support services from secondary care. They also made the distinction between two kinds of practitioner within these categories: those with a more biomedical orientation and those with a more psycho-social orientation, which they labelled "primary clinicians" and "family doctors" respectively.

More recently, in a comparative study of patients' accounts of deciding to consult their GP in two urban and two rural general practices (one small, one large in each category), Farmer et al. (2006) found that urban and rural patients made different decisions as to when to consult their GP in response to particular medical symptoms. Farmer et al. (2006) suggested that variation in decisions to consult were related to the perceived strength of 'relationship' patients felt with their GP. Farmer has since defined this relationship as "connectedness", meaning that "patients and health professionals have mutual personal and contextual knowledge that reaches beyond healthcare transactions" (Farmer, 2007, 226). Their study suggested that the relationship was strongest in the small rural general practice and weakest in the large urban practice (Farmer et al., 2006, 215). Farmer et al. (2006) suggest that, from the patients' perspective, the nature of patient- practitioner relationship is significantly different between urban and rural locations. Hence, one might expect the experience and meanings associated with receiving care to also vary between urban and rural practices.

Similarly, the practice's location and the socio-economic background of its patient population also seem to be related to the care provided. The inverse care law proposed by Tudor-Hart (1971), states that the "availability of good medical care tends to vary inversely with the need for it in the population served" (1971, 405), patients in practices in more deprived areas tended to receive poorer care. Recent studies (Mercer and Watt, 2007) argue that the inverse care law continues to perpetuate itself. Mercer and Watt's (2007) questionnaire-based comparison of patients' experiences of attending general practices in deprived and affluent areas has shown that patients in the most deprived areas continue to have more health problems than those in affluent areas. Their appointments also tend to be shorter, more difficult to access and are with GPs who report themselves to be more stressed (Mercer and Watt, 2007). Therefore, one might suppose that the organisation and provision of diabetes care between practices in deprived and affluent areas might also vary. Indeed, Goyder et al.'s (2000) historical cohort study of patients' records noted that the likelihood of attending a diabetes review appointment in general practice was reduced in areas of higher deprivation. This has probably changed significantly with the introduction of the nGMS contract's financial incentives to provide diabetes care in general practice. However, McLean et al. (2006) have found that, when exception reported patients are taken into account, practices in areas of greater socioeconomic deprivation continue to perform less well in the more complex measures of QOF, such as achieving targets for glycaemic control in diabetes. As they (McLean et al., 2006) observe, this shows a continuation of the inverse care law. It also suggests that there is continuing variation in the diabetes care provided in affluent and deprived practices.

Similarly, in Campbell et al.'s (2001a) questionnaire-based study of practices of differing size, they found that the average length of the consultations was inversely proportional to the number of patients per GP. Patients at practices with smaller list sizes reported better accessibility of care, better performance of practice receptionists and more continuity of care in the doctor-patient relationship (2001a). However, a separate observational study by Campbell et al. (2001b) suggested that larger practices were more

successful in meeting clinical quality indicators. For example, larger practices where staff reported a better "team climate" were more successful in carrying out the various clinical review tasks involved in diabetes care (Campbell et al., 2001b). From these studies one might conclude that practice size is related to variation in the care patients' experience in general practice, including in the provision of diabetes care. Finally, as I will now go on to discuss, the "ethos" of a general practice may also influence the approach taken to providing both generic care, and care for diabetes.

General Practice Ethos

Armstrong has theorised that variations in the spatial and temporal organisation of general practice reflect the movement of the Foucauldian clinical gaze (Foucault, 1973) from the sick, individual body of the patient, to monitoring the wider health and behaviour of the community in relation to the norms of the population (Armstrong, 1985; 1995). According to Armstrong (1995), medicine no longer considers health as the absence of disease; it focuses on the risk factors of illness. Hence, one is never fully healthy but existing at a point on a continuum between health and illness, always at risk of future illness, which is in itself located within the community and "lifestyle" of a person (Armstrong, 1995). He argues that the old fashioned general practice was "a domestic activity inseparable from the bodies it treated and barely differentiated from lay domestic care" (Armstrong, 1985, 660). The new general practice has "shifted from a spatial to a temporal model of illness" emphasising a "population constantly at risk, chronic illness, prevention, health promotion", all celebrating the temporal trajectory of illness (Armstrong: 1985: 664). Hence, from this perspective, differences in approach between general practices might be understood as differences in the stages of the move from the 'old' 'domestic' general practice to the 'new' community orientated health centres.

However, this seems somewhat over simplified. Based on in depth interviews with GPs in London, Green (1996) has since challenged Armstrong's (1985) hypothesis. She suggests that the differences in GPs' use of time and perception of 'community' are

based on differences between single-handed GPs and multi-partnered practices. She identifies differing understandings of the role of general practice in the 'community'; in providing continuity of care; in their approach to holistic care, and in the autonomy of the GP (Green, 1996). Green (1996) suggests that the differences in approach in general practice are a result of GPs emphasising different characteristics within the ideals of the discipline as a whole. Green's (1996) conclusion is supported by Huby et al.'s (2008) recent ethnographic comparative study of four general practices (2008) following the introduction of the nGMS contract. Huby et al. (2008) approach each practice as an organisation and drawing on Weick's (1995) theory of organisational sensemaking, show that at each general practice the various members of that practice presented a 'story' about the organisation. This included "the approach to general practice work, organisation of the practice, the values underpinning this approach, and where this approach would lead them in the future" (Huby et al., 2008, 64).

Huby et al. (2008) identify four strands or ideals being used either individually or in combination to inform these practice 'stories'. The first practice focused on holistic care, the patient-professional relationship and continuity of care in the style of "traditional family medicine" (Huby et al, 2008, 72). The second on general practice's role in public health, emphasising population screening and practice initiated visits to patients' homes to provide immunisations and follow-up. The third practice saw itself as combining continuity of care and holism through personal lists, with the ability to adapt to change and be at the forefront of developments. The fourth one defined itself as a business providing up to date modern care services. Each practice emphasised a different defining feature of general practice identity (Huby et al., 2008).

Given the diversity of general practice and the ways in which policy instruments such as guidelines and care pathways are interpreted and incorporated into everyday clinical practice, one might expect to find variation in the way in which practices organise care for diabetes. Indeed, in Pooley et al.'s (2001) semi-structured interviews with type 2 diabetes patients and their health professionals they found considerable variation in the way different general practices organised their diabetes services. Pooley et al. report that

some general practices set aside time for running separate diabetes clinics, others saw patients during normal surgery and still others saw patients with diabetes on an opportunistic basis. At some practices one GP or practice nurse within the practice specialised in diabetes, while in others, patients saw their normal GP and elsewhere patients received most of their care from a hospital based clinic. In addition, there were variations in the provision of podiatry, dietetics, and eye screening. However, whilst Pooley et al. (2001) present an analysis of what were considered the pros and cons of diabetes care across their 85 interviews these cannot be related back to the organisation of care at particular practices. In contrast, this thesis intends to consider patients' and professionals' experiences of receiving and providing care in the context of particular organisations and hence, better understand how the context of the general practice might influence these experiences. Moreover, Pooley et al.'s (2001) study was carried out before the introduction of the nGMS contract and as I will now go on to discuss this might be expected to have had a significant influence on the organisation and provision of diabetes services in primary care.

Implementation of the new GMS contract

As discussed in the introduction, the new GMS contract introduced in 2004 made various changes to the way in which British general practice is remunerated and in the services practices are expected to offer. The Quality and Outcomes Framework has particularly influenced the reimbursement practices receive for providing chronic illness services and prompted various organisational changes within general practice.

Shortly after the introduction of the new GMS contract in 2004, Roland et al. (2006) used in-depth interviews and a questionnaire survey to outline the initial impact of the QOF incentives on general practice organisation. They observed that the contract had furthered the long term trends of practices employing more nurses to carry out chronic illness clinics and triage minor illness and more data entry clerks, administrative staff and health care assistants. Practices were also establishing more recall systems for patients with chronic illness alongside improved data collection through the increased

use of computerised clinical records. Whilst the GPs were generally positive about the potential health gains of such measures, Roland et al. (2006) also outline various concerns over the potential unintended consequences of the contract. They suggested that the contract encouraged a move towards specialisation and away from the traditional generalist and holistic approach of general practice. They were also concerned that, with the increased role of nurses conducting different clinics for various illnesses, there was a potential to undermine the continuity of care (Roland et al., 2006).

Research on the impact of the nGMS contract on general practice has been conducted by a range of scholars many of whom have focused on drawing comparisons between practices' QOF performance (for example, Wang et al., 2006; Guthrie et al., 2006; McLean et al., 2006). However, one group of researchers in particular has focused on the contract's impact on the organisation and ethos of four general practices differing in size, location and identity. They have published various papers based on these linked ethnographic studies of two Scottish and two English general practices (Checkland et al., 2008; Grant et al., 2009; Huby et al., 2008; McDonald et al., 2008; McDonald et al., 2007). These papers highlight similarities and differences in the way in which the nGMS contract has been incorporated into everyday care in the context of differing cultures and organisations of general practice. As a whole they illustrate that, although practices tended to employ different organisational solutions to meet QOF targets, the resulting effects of making these changes were broadly similar (Checkland et al., 2008). For example, although, Huby et al. (2008) identified that each practice had a different "story" or ethos, they had adopted broadly similar organisational forms in response to the QOF. Whilst the different professionals had taken on the responsibility for meeting the QOF targets at each practice, there was a general pattern of some clinicians being more active in meeting the targets than others. In all practices clinicians were also being subject to increased surveillance from their colleagues and adopting higher levels of self-surveillance in response to the QOF. This was facilitated by the increased use and ease of access to data through computerised clinical record systems and reports produced by the increased number of IT staff and practice managers (McDonald et al.,

2007, 2008). In addition, each practice showed signs of becoming divided to contain "elite multidisciplinary groups" around clinical target areas. Yet, these organisational changes had not changed the dominant practice "stories" or organisational self-presentations (Huby et al., 2008).

These techniques of surveillance, alongside the increased routine nature of some QOF tasks, meant that clinicians' work, in QOF related areas, was less variable and those aspects which were viewed as less specialised were passed down a hierarchy of professions from doctor to nurse to health care assistant (Grant et al., 2009). Both doctors and nurses drew on their increasing specialisation in disease areas and claims to provide holistic care as discourses to maintain their position in the professional hierarchy, whilst passing on "dirty" routine work to the level below.

This argument is similar to Abbott's (1988) theory of the professions discussed above. However, whilst Abbott (1988) would suggest that passing on "dirty work" would maintain traditional boundaries, Grant et al. (2009) suggest that this is only superficially true and that the shifting organisation of work is subtly changing the hierarchy of the professions. According to Grant et al. (2009), the reorganisation of work cuts across professional boundaries, between GPs and managers, as clinicians had to take closer account of the business and financial implications of their clinical practice. Also, the role of practice nurses taking the lead in financially incentivised clinical areas such as diabetes meant that some GPs were excluded from decision making in these areas (2009).

Finally, Checkland et al. (2008) highlight the implications of nGMS changes for patients' care. Like Huby et al. (2008) they highlight a discrepancy between these health professionals' presentations of their care and the organisational changes in the practice in response to QOF. In particular they argue that although the health professionals continued to claim to provide holistic care, changes in the organisation of the general practices were leading to an increasingly narrow biomedical focus in care provision (Checkland et al., 2008). For example, they suggest that the more developed recall

systems created in response to QOF may place a burden on patients and construct them as "passive, disease bearing objects who need to be prompted and reminded to attend care" (Checkland et al., 2008, 795). In addition, clinicians involved in the study suggested that their consultations had become "more systematic" in response to the active part played by prompts from the computer system to perform particular financially incentivised tasks (Checkland et al., 2008). Moreover, with the demands of meeting targets for clinical outcomes, Checkland et al. (2008) suggest that patients post-QOF may be receiving more medications.

Whilst the QOF did not seem to be affecting the overall ethos at each practice or claims to holism as a whole, it has had a substantial effect on the organisation and provision of care in the practices studied by Checkland et al. (2008), and seems to be promoting a more biomedical construction of the patient. These papers (Checkland et al., 2008; Grant et al., 2009; Huby et al., 2008; McDonald et al., 2008; McDonald et al., 2007) are significant in furthering our understanding of inter-professional relationships and the impact of QOF on the organisation and delivery of clinical care from the perspective of the professionals. However, none of these papers considers how patients might interpret changes apparently being driven by QOF, such as seeing a nurse instead of a GP, or receiving more medications. This is something which I will explore in this thesis.

Equally, they do not consider how organisational factors may influence clinical decision making when faced with individual patients, nor how professionals' conceptualisations of a particular condition and their role in its management might influence the way they provide care. These concerns have been taken up by researchers focusing more specifically on the organisation of diabetes care which I will now go on to discuss.

Organisational and other influences on professionals

Based on her analysis of professionals' approaches to assessing and promoting patient adherence to regimens of self-care in two American endocrinology clinics, Lutfey (2003) argues that clinicians' assessments of compliance, and hence their approach to patient involvement and self-care, are influenced by the organisation of the clinic. For

example, Lutfey (2003) notes how one hospital's reliance on temporary staff was associated with poor continuity of care and professionals' heavy reliance on HbA_{1c} test results to assess patients' adherence to regimens of self care, rather than patients' own accounts of their behaviour. In addition, professionals were less keen to try starting new treatments because they knew that they would be unlikely to see that patient again (Lutfey, 2003, 71). Informal interactions between the health care providers also influenced the consulting clinician's perceptions of individual patients and hence decisions made within the consultation. Hence, Lutfey (2003) demonstrates that various aspects of the organisation of health care can directly affect professionals' interaction with patients and the clinical decisions made. This suggests that the organisational changes observed by Huby et al. (2008) may directly influence the clinical decisions primary healthcare professionals make in providing diabetes care; however, this has yet to be researched.

In addition, professionals' preconceptions about the disease and medications may also influence their clinical decisions. Lutfey (2005) noted that clinicians adopt a variety of strategic approaches in trying to encourage patient adherence to regimens to self-care. She argues that we should not just consider patients' behaviours in trying to understand compliance with regimens of self-care, but the actions of their professionals as well (2005). Similarly, May et al. have argued, "how family doctors conceptualise chronic illness in the consultation has important implications for both the delivery of medical care, and its experience by patients" (May et al., 2004). GPs' moral judgement of the legitimacy of the patients' complaint, the possibility of its resolution through cure or referral, and the doctor's empathy with the patient were particularly salient in framing their approach to the consultation (May et al., 2004).

Hence, how health professionals conceptualise type 2 diabetes may influence the care they provide. Using mixed qualitative methods to record American family doctors' narratives around type 2 diabetes Loewe et al. (1998) found that, based on their experiences in hospital rotations as junior doctors and stories from other medics, many seemed "horrified by the disease and ambivalent about the standard medical treatment"

(Loewe, 1998, 1273). However, they did not want to impart this pessimism to patients and continued an optimistic tone in consultations. Ultimately, though, the professional's perspective of the disease and the impossibility of effectively controlling it, shaped the approach professionals adopted in encouraging self-care and in prescribing medications, despite their attempts to overlay these with a positive outlook.

The care which patients experience, in terms of what medications they are prescribed, also seems to be related to professional perceptions of that medication, particularly insulin. Results from the international Diabetes Attitudes Wishes and Needs (DAWN) study (Peyrot et al., 2005) showed that many health care providers were reluctant to prescribe insulin, with primary care professionals being more reluctant than specialists. Peyrot et al. (2005) also noted that in countries where providers seemed more hesitant to prescribe, patients were also more resistant to using insulin. They suggest that "beliefs about insulin are related to the cultures and health care systems of different countries and understanding beliefs about insulin will require understanding how these factors operate" (Peyrot et al., 2005, 2677). Patient and professional attitudes towards the drug seem to be related. However, due to the broad reaching survey approach of this study it is unclear whether this is because both draw on a shared cultural perception of the medication or because the attitude of the professionals influences that of the patients or vice-versa.

However, Hunt et al.'s (1997) qualitative study of Mexican-Americans with type 2 diabetes sheds some light on the relationship between patient and professional attitudes towards insulin. They found that health care providers often unwittingly acted as sources of negative attitudes towards starting insulin through their use of the drug as a threat to promote compliance with prior treatments (Hunt et al., 1997). Clearly the way in which professionals perceive the drugs they are prescribing may have a significant influence on the way patients also experience them.

Considered together, these studies (Loewe, 1998; Hunt et al., 1997; Lutfey, 2003, 2005; Peyrot et al., 2005) suggest that organisational factors and health professionals'

conceptualisations of the disease and its treatments may affect the way in which health care for diabetes is provided. So influencing the healthcare experienced by patients.

Summary

In summary, the literature above indicates that, in order to understand how health policy instruments are implemented it is necessary to understand how they are interpreted by health professionals and applied within particular, local contexts. In the case of type 2 diabetes, the majority of routine care has been devolved to primary care; however, the organisation of general practice, a core part of primary care, is apparently becoming increasingly standardised in the wake of the nGMS contract. Research has yet to consider whether this has also led to a standardisation of diabetes care organisation and how this may influence patients' experiences of diabetes care. In general, the studies outlined above focus on the impact of instruments of 'clinical governance' on health professionals' autonomy and the organisation of general practice. They focus on the perspective of the health professional and do not consider the meanings which patients might associate with organisations of care and treatment decisions. However, as I will now show, much research into patients' experiences of type 2 diabetes has equally tended to focus on how patients' experiences are influenced by their wider lives rather than through any interaction with the health services.

Living with and in spite of type 2 diabetes

Various studies within the sociology of health and illness which consider the influence of the health services on patients' experiences of illness have often approached this through Foucault's (1978) notions of bio-power and the construction of patients as self-disciplining subjects around the norms defined by a dominant biomedical discourse (cf. Comaroff, 1982; Gastaldo, 1997; Lupton, 1997; Peterson and Bunton, 1997; Turner, 1997). Foucault's work has been highly influential in medical sociology; however, whilst not rejecting his illustrations of the socially constructed nature of illness and the body (1973) and the operations of tacit and diffuse systems of power (1978), I will not draw explicitly on his work in this thesis. This is because Foucauldian approaches

appear to overemphasise the role of biomedicine, whilst Blaxter (1983) has shown, experiences of health care form only one part of a person's understanding of illness. Blaxter's (1983) study of women's causation theories illustrates that people use biomedical explanations and constructions of disease as one of several explanations for illness. Biomedical constructs are selectively incorporated into understandings of illness which, are also informed by a person's experiences and expectations of being ill within their particular social and cultural context (Blaxter, 1983; Riessman, 1990; Williams, 1984). Moreover, Foucauldian approaches often present medicine as a homogenous field (Ferzacca, 2000) and I am interested in exploring contextual variation in the provision of care for type 2 diabetes and variation in how health professionals themselves understand the disease and how this interrelates with patients' perceptions and experiences.

The sociology of chronic illness has strived over the past thirty years to adopt an "insider perspective" which focuses on people's subjective experiences of living with illness in the context of their wider lives and biographies and the meanings they associate with that illness (Conrad, 1990; Lawton, 2003). Work in this area has added to knowledge of patients' experiences of illness in various ways. For example, Cornwell (1984) and Blaxter (1983) both demonstrate the importance of social context in informing people's perceptions of what constitutes health and illness and the causes of disease. Research has also shown that people with chronic illness may strive to appear normal and hence avoid the fear of being stigmatised (Scambler, 1986) and may normalise the experience of symptoms as part of everyday life and hence not view themselves as ill (Pattenden et al., 2002). The view that the onset of chronic illness involves a "biographical disruption" (Bury, 1982) potentially leading to a "loss of self" (Charmaz, 1983), has also been particularly influential in the sociology of chronic illness (Lawton, 2003; Williams, 2000). However, as various studies highlight, the onset of chronic illness is not always considered a disruptive experience and the disruptiveness of illness is linked to the meaning it carries within the context of a person's biographical history and culturally and personally anticipated lifecourse (Carricaburu and Pierret, 1995; Pound et al., 1998; Sanders et al., 2002). For example, Carricaburu and Pierret (1995) noted that the

diagnosis of HIV amongst asymptomatic haemophiliac and homosexual men had the effect of reinforcing aspects of their biographies. The diagnosis of HIV was interpreted through the context of their existing identities built around haemophilia or homosexuality and, as such, reinforced these (Carricaburu and Pierret, 1995). Pound et al.'s (1998) study of experiences of stroke amongst elderly, working class people suggested that for "people already accustomed to hardship, illness and death… stroke was not experienced as an extraordinary event" causing biographical disruption but a "normal crisis" (Pound et al., 1998, 500). Similarly, Sanders et al. (2002) drew on Bury's (1988) conceptual distinction between "meaning as consequence" (for example, restricted social or physical activity) and "meaning as significance" (the symbolic meanings a condition carries within a particular cultural context) to better understand older people's experiences of osteoarthritis. They found that, whilst osteoarthritis had major consequences of pain and restricted people's daily lives, people played down the significance of the condition as a normal part of old age. A person's biography and the point in their lifecourse at which illness is encountered are clearly influential factors in shaping the "significance" of a condition, and disruption can occur in two interrelated ways, one physical and the other social and symbolic. As I will outline below, studies of people's experiences of type 2 diabetes have followed similar lines of enquiry, focusing predominantly on patients' experiences of, and meanings attributed to, the condition within the context of their wider lives.

Perceptions of type 2 diabetes

As found in research into people's perceptions of other illnesses, people's perceptions of the severity of type 2 diabetes were informed by their prior experiences of seeing friends and family with the condition, and their expectations for their own life and health. Peel et al.'s (2004b) study of people's reactions to the diagnosis of type 2 diabetes found that there was considerable variation. This, Peel et al. (2004b) showed, was related to the trajectory people followed to diagnosis. Diagnosis was not met with 'shock' or negative emotions when diabetes was already suspected, or when the person was relieved to find that they did not have something worse. Shock and negative emotions were only

reported amongst people who were asymptomatic and identified through routine screening procedures, and hence, had not suspected any kind of illness. Peel et al.'s study suggests that reactions to the condition are influenced by the person's biography; for example, if they were related to other people with diabetes and therefore suspected that they might also have the condition. Similarly, others have found that people who were diagnosed in later life tended to view the condition as less serious, whilst those who had witnessed friends and family suffering from the condition were more likely to view the condition as serious (Murphy and Kinmonth, 1995; Savoca et al., 2004). Similarly, according to Savoca et al. (2004), physical changes, such as the onset of the disease's complications, were taken as signs of severity and disease progression. Patients who viewed their condition as serious tended to be more motivated towards adopting strict regimens of self-care to avoid the long terms complications of the disease (Savoca et al., 2004). In contrast, those who did not view the condition as serious in their particular case, tended to aim their self care towards the avoidance of the "symptoms" of the condition (Murphy and Kinmonth, 1995).

In addition to these studies which link patients' perceptions of their condition to their biography, social context and direct experience of the illness, one study has also observed a relationship between doctors' reactions to patients' emotions at the time of diagnosis and the patient's perceptions of the severity of their condition (Dietrich, 1996). Dietrich's (1996) observations suggest that health professionals' reactions might influence people's perceptions of diabetes. This hypothesis does not seem to have been explicitly pursued in subsequent research.

Ascribing meaning, suggesting causation and enacting self-care regimens

In a similar vein to research on other conditions (e.g. Sontag, 1978), various studies consider the meanings people associate with diabetes in a variety of cultural contexts. Studies based in a non-Western setting show that explanations based on biomedical, Western, perceptions of diabetes are of limited value in providing culturally and morally meaningful explanations for the condition (Garro, 1995; Mercado-Martinez and Ramos-

Herrera, 2002; Sunday et al., 2001). In addition, others highlight that biomedical explanations of type 2 diabetes which emphasise lifestyle as a causal factor are associated with a moral discourse around notions of "control" and Western notions of individual autonomy (Broom and Whittaker, 2004; Ferzacca, 2000; Garro, 1995). Lifestyle explanations of type 2 diabetes imply that the condition is linked to socially unacceptable 'risky' behaviour involving "self-indulgence and lack of self-discipline" (Lupton, 2003, 99). Hence, as a way of countering the socially stigmatising lifestyle explanation, patients often suggest alternative theories of causation which explain the condition through their own biographies and enable a more positive presentation of self (Broom and Whittaker, 2004).

Taking a slightly different approach, there has also been much research aimed at explicating reasons for type 2 diabetes patients' (non-)compliance with biomedically prescribed regimens of self-care. One explanation posited for non-compliance focuses on the role of 'lay' causation theories. Various studies argue that causation accounts and how they negotiate the implied responsibility for the condition are predicators of patients' reported compliance with regimens of self-care in other studies (Hunt et al., 1998; Parry et al., 2005; Savoca et al., 2004; Schoenberg et al., 1998). This research shows that people who view their own behaviours as a cause or "provoking factor" (Hunt et al. 1998) of their condition, or emphasised explanations of lifestyle over those of inheritance and genetics, present themselves as compliant/ more active in self-care (Hunt et al., 1998; Parry et al., 2005; Schoenberg et al., 1998). These studies also argue that this is due to people's perceptions of the disease being within (internal) or outside (external) their control.

However, perceptions of diabetes and reported practices of self-care are not only based on causation theories. Savoca et al.'s (2004) interview based study with type 2 diabetes patients with particularly poor and particularly good glycaemic control shows that various other factors also affect patients' perceptions of their illness, reported practices of self care and glycaemic control. These include: causation theories, acceptance of the consequences of the condition, and experiences of physical changes. Similarly, Cohen et

al.'s (1994) comparison of the explanatory models (EMs) of patients and health practitioners shows that whilst practitioner conceptualisations of diabetes and its management are orientated towards the disease, patients' models are much more orientated towards the social aspects of illness.

The cognitive approach of studies such as Hunt et al.'s (1998) and Schoenberg et al.'s (1998) is limited as it sidelines the role of the social contexts of people's wider lives, which are also shown to have a significant influence on their compliance with regimens of self-care. Studies which have focused on the role of patients' social context as a barrier or facilitator to compliance will be discussed in the next section; however, before moving on I will highlight a few other limitations of the cognitive approach to understanding patient compliance adopted by Hunt et al. (1998) and Schoenberg et al. (1998).

Firstly, it is significant that in investigating only the patients' attitude towards their condition these studies also implicitly problematise the patient but not the health care they receive and how this may also inform their perceptions (Hunt and Arar, 2001). Also, the cross-sectional approach of these studies (Hunt et al., 1998; Schoenberg et al., 1998) fails to consider what factors might influence patients' causation theories over time. Indeed, in Hunt et al.'s (1998) study they hypothesise that causation models may be altered in light of experience of the condition and, in an analysis focusing on causation theories, rather than compliance, Lawton et al. (2008b) have since shown this to be the case.

In a longitudinal study drawing comparisons between the causation theories proposed by the same people with type 2 diabetes shortly after diagnosis and four years later, Lawton et al. (2008b) discern a general shift in orientation from what (following Rotter 1954) can be considered "internal" to "external" explanations of their condition. Patients shifted from using explanations in which they held themselves or their previous actions in some way responsible for their condition, to causes which were outwith their control, such as ageing or inheritance. In addition, Lawton et al. (2008) suggest that shifts from

"internal" to "external" explanations seemed to result from patients' assessments of the efficacy of their treatment regimens (the observed effects of diet and tablets perceived through self blood glucose monitoring), perceptions of disease progression (indicated through extremely high blood glucose levels and changes in their treatment regimen), and ways of legitimating their approach to self-management at the time of the final interview.

Whilst Lawton et al.'s (2008) study shows that explanations for the condition remained rooted in the patients' lifeworlds, I would also highlight that two out of the three experiences of the disease, which Lawton et al. (2008) identify, are mediated by the health care received. The success of treatment and diet would not be so immediately visible to patients had they not been provided with blood glucose monitors or informed of their HbA1c results. Equally if changes in medications were not provided then again the experience of the condition might differ; for example patients might experience more 'symptoms' and more complications at an earlier stage. Diabetes would be experienced as a much more acute disease. Moreover, this study implies that 'treatments' in themselves are significant in informing patients' perceptions of their condition, which I will go on to discuss.

These studies outlined above have focused on patients' perceptions of their disease, and (with the exception of Lawton et al., 2008) how these relate to compliance with prescribed regimens of self-care. However, as mentioned above, there has also been much research on how patients' socio-economic and cultural circumstances act as barriers and facilitators to the adoption of regimens of self care in everyday life.

Social contexts, as barriers and facilitators to self-care

It has long been shown that compliance must also be understood within a patient's social and cultural context. Drummond and Mason's (1990) interviews with people with diabetes highlight that the adherence to regimens of self care interplays with many other considerations and choices in their everyday lives. Finances, work, family relationships

and emotions all compete for attention. These factors all inform and constrain patients' decisions in everyday self care at any one time (Drummond and Mason, 1990).

Similarly, Anderson et al.'s (1995) interviews with 196 women with diabetes, show that whilst women from differing cultural backgrounds attach different meanings to their diabetes, these cognitive models were not the most important influence on their day to day management of their diabetes. Access to social and financial resources, and the circumstances of their daily lives had a much greater impact. For example, eating at regular times could be inhibited by work patterns, and support from friends and family could facilitate exercise and diet (Anderson et al., 1995).

Hepworth et al. (1999) also demonstrate that gender can influence a person's compliance with regimens of self-care. They show that the gender role of women in family contexts, in caring for others as wives and mothers, can impede their capacity to care for themselves. For example, women in several studies (Bissell et al., 2004; Hepworth, 1999) report that meeting both their spouse's food preferences and maintaining their own diet could be difficult, time consuming and financially burdensome. Maclean's (1991) interviews with insulin treated patients also shows that patients perceived a social stigma arising from having a different eating pattern and diet which inhibited their social activity. Maclean (1991) points out that individual food preferences and cultural eating patterns can have a great influence on patients' adherence to dietary advice. Finally, Schoenberg et al.'s (2005) in depth interviews with people diagnosed with diabetes from a range of ethnic backgrounds highlight that stress is perceived to intersect with diabetes in various ways which may impede self-care and/or glycaemic control. In addition, Schoenberg et al. (2005) show that stress in itself can be enhanced by attempts to stick to a regimen of self-care in difficult social and economic situations. This stress can then also directly influence blood glucose levels according to the people interviewed.

These studies highlight the complexity of the experience of living with diabetes on a daily basis and how disease management is influenced by multiple factors from a person's wider life. In reviews of the literature on patients' experiences of diabetes,

Campbell et al. (2003) and Paterson et al. (1998) summarise the multiple factors which have been identified in influencing patients' experiences of living with diabetes and adherence to regimens of self care. Based on the literature both reviews argue that effective self-care in diabetes in fact depends on actions of "strategic non-compliance", or "cheating" though which people come to understand the effects of their self-care regimen and adapt it to their lifestyle rather than vice versa (Campbell et al., 2003; Paterson et al., 1998). Through "cheating" patients assume an active role in managing their own condition, and aim to achieve a balance between the demands of managing diabetes and living a 'normal' life (Paterson et al., 1998).

Paterson et al. (1998) also observe that when patients feel known and valued as knowledgeable individuals by their health professionals, rather than being scolded for non-compliance, this can help foster reaching a balance between practices of self-care and living a 'normal' life. However, Paterson et al. (1998) do not go on to reflect on the factors which might influence a professional's approach to a patient with diabetes. For example, I have pointed out in the literature reviewed in the first half of this chapter, that professionals' approach to patients can be influenced by their own conceptualisation of diabetes and organisational factors (Lutfey, 2003; Loewe, 1998).

In addition, the studies reviewed by Paterson et al. (1998) and those outlined above, tend to take little account of other ways in which interactions with the health services might influence patients' daily experience of living with diabetes. They tend to focus on regimens of self-care, but not what shapes the context of the interaction in which regimens and treatments are prescribed and whether this might also influence compliance. Nor do they consider the impact and influence of organisational factors, such as how frequently a patient receives care for their diabetes. Some research has, however, begun to consider the role of interactions with the health service in influencing patients' experiences and perceptions of chronic illness. I now turn my attention to these studies, and how this thesis hopes to contribute to them.

Influences of health services on the experience of chronic illness

Studies of chronic illness from the 'insider perspective' have illustrated the importance of the social and cultural context, biography and the point in someone's lifecourse at which illness is experienced in informing both perceptions and experiences of chronic illness (Lawton, 2003). However, various studies have suggested that interactions with the health services can have a significant influence on a person's experience of living with a chronic illness (Hart, 2001) and their perceptions of that illness through the meanings attributed to health care organisation and delivery (Lawton et al., 2005b).

Hart's (2001) study of stroke survivors suggests that future work in the sociology of chronic illness should reconsider the health services as a significant aspect of the illness experience. Based on in-depth interviews with stroke survivors, Hart suggests:

> People's responses to living with a stroke involve far more than simply a response to their condition… [they] also involve a response to the way health and social care services are organised and delivered (Hart, 2001, 102).

Hart shows how interactions with the health service could have a direct effect on the daily and embodied experience of recovering from stroke. For example, not being referred to the stroke rehabilitation unit meant that patients might not physically recover from stroke as effectively as might otherwise have been the case (Hart, 2001, 112). Similarly, prioritisation of referrals between departments could also mean that patients failed to receive sufficient care and hence experienced physical setbacks in their recovery (Hart, 2001, 113). The health system, professionals' actions as "street level bureaucrats" (Lipsky, 1980, cited by Hart, 2001,120), and failures of referral between professionals left patients to fall through cracks in that system and directly affected patients' embodied experiences of life after a stroke. Clearly, the organisation and delivery of health services also have an influence on people's experiences of chronic illness and this thesis will continue in a similar vein to investigate how services influence the experience of type 2 diabetes.

As I will now outline, previous research implies three ways in which interactions of the health services may influence patients' experiences and perceptions of diabetes: through the use of medications, through involvement in treatment decisions, and through the organisation of care both in terms of providing coordinated care and in the meanings patients ascribe to when, where and which health professional they consult.

Medications and monitoring

Patients' use of a blood glucose monitor has been presented as a way in which they judge the effectiveness of their treatment regimen and the state and progression of their condition (Lawton et al., 2008b), or came to recognise the bodily symptoms of high and low blood glucose (Mol and Law, 2004; Paterson, 2001b). As such, this piece of equipment "mediates" (Law, 1992) the person's understanding and interpretation of bodily signs of the condition, ascribing meaning to embodied experience, and hence forms part of the experience of having that condition[5].

Studies focused on understanding the patients' perspective of self monitoring of blood glucose (SMBG) record ambivalent views of its usefulness (Peel et al., 2007; Peel et al., 2004a). Peel et al.'s study of the attitudes towards SMBG amongst patients newly diagnosed with diabetes and again four years later, indicated that self monitoring does not always encourage people to adopt a more active role in self-care (Peel et al., 2007; 2004a). They (Peel et al., 2007) report that whilst for many patients being able to use the monitors gave helpful evidence of the continuing presence of their diabetes, the majority of patients four years after diagnosis had reduced their blood glucose monitoring and tended not to take action on the basis of their blood glucose readings. This was often because their health professionals had not shown any interest in the results and provided

[5] However, self-monitoring of blood glucose (SMBG) for people with non-insulin treated type 2 diabetes is a highly contested subject from a clinical perspective because it is reported to be of dubious efficacy in reducing HbA_{1c} measures (Davidson, 2007; Davis et al., 2007; Farmer et al., 2007; Poolsup et al., 2008).

insufficient guidance about their interpretation. This again indicates the important role which interactions with the health services can have on experiences of managing type 2 diabetes (Peel et al., 2007).

As discussed in the introduction, as type 2 diabetes progresses patients are likely to be prescribed oral glucose lowering agents (OGLAs). Adherence to oral glucose lowering agents (OGLAs) has been found to be poor, and increasingly worse the more tablets are prescribed (Donnan et al., 2002). Various studies (Pound et al., 2005; Conrad., 1985) of patients taking tablets for other chronic illnesses such as asthma have found that patients are often cautious about taking medications. They may weigh up perceived pros of their use against the cons of their side-effects and the limitations they may bring to daily life. Patients have also been found to express concerns about the long-term use of medications (Pound et al., 2005).

However, few studies (Lawton et al., 2008) have also focused specifically on the meanings which people associate with oral glucose lowering agents (OGLAs). Lawton et al.'s (2008a) longitudinal, interview based study shows that patients may be suspicious of starting to take oral glucose lowering agents, because they view starting to take tablets as the start of a slippery slope of disease progression and experience side-effects of the drugs such as "wooziness". However, when these side effects are alleviated and patients see the effectiveness of the drugs through self monitoring of blood glucose, Lawton et al. (2008a) argue that patients are motivated to take their medications.

There has been more research into attitudes towards initiating insulin and what has been termed "psychological resistance" to insulin amongst patients and professionals (Hunt et al., 1997; Peyrot, 2006; Polonsky et al., 2005). Hunt et al.'s (1997) interviews with Mexican-American patients show that whilst some patients may recognise the efficiency of insulin in helping them to feel better and in avoiding long term complications, negative attitudes towards the drug were much more common. Interestingly, Hunt et al. (1997) show that these negative attitudes often result from health care providers using

initiating insulin as a threat to promote compliance. Negative views of insulin include: the perception that insulin indicates a more advanced stage of the condition, feelings of failure and self blame, and the perception that insulin leads to complications such as blindness (see also Brown et al., 2002; Nakar et al., 2006; Snoek, 2002). In addition, the stigma and practicalities of the injection itself and the associated side effects of hypoglycaemia may create a sense of fear and concern over the everyday "hassle" and "enslavement" of having to take insulin at specified times (Hunt et al. 1997). In addition, it has been suggested that the constant attention required to avoid hypoglycaemia when using insulin is associated with a reorientation to how one experiences and works on one's own body (Mol and Law, 2004). Hence the prescription of insulin by healthcare professionals can have a direct effect on patients' perceptions and experiences of living with diabetes. Similarly, the blood glucose monitors and OGLAs provided by the health services form part of the wider experience of living with diabetes because they inform patients' perceptions of the severity and progression of their condition.

Health services may also influence patients' experience of diabetes through the role which the person with diabetes is expected to play as a patient, for example being involved in clinical decisions.

Changing relationships and patient empowerment

Various researchers have suggested that an equal partnership between patient and professional is an ideal for healthcare to aim for, but which is, as yet, rarely experienced by patients (Anderson and Funnell, 2005; Bissell et al., 2004; Paterson, 2001a). Moreover, other research suggests that not all patients want to be involved to the same extent or adopt responsibility for their condition to the same extent and therefore the desired patient-professional relationship is variable (Say et al., 2006; Thompson, 2007). Say et al.'s (2006) review of studies of patients' experiences of involvement in clinical decisions shows that the desire to be involved is affected by factors such as age, sex and education, experience of illness over time, the severity of the illness, the type of decision being made, and the patient's relationship with, and trust in, their health provider.

Similarly, Thompson suggests that the level of involvement considered desirable by patients depends on the context of their health needs, their personality and their trust in their health professional, all of which will vary over time (2007). Entwistle and Watt (2006) add that involvement can mean multiple things, and be undertaken in different ways depending on the context and the thoughts and feelings of the people involved. They also suggest that patients "who believe that their clinicians care about them… and are making effort on their behalf, sometimes report being encouraged or inspired to try to do their own bit in relation to their health care" (Entwistle and Watt, 2006, 273). Furthermore, in Entwistle et al.'s (2008) research into type 1 and 2 diabetes patients' experiences of involvement, they found that patients frequently cite features of the 'feel' of consultations as encouraging involvement. They observe that involvement is more likely when professionals were perceived as friendly, interested and respectful of their patients, facilitate patients' contributions to discussions and are not unduly judgemental (Entwistle et al., 2008, 367).

However, rather than considering these findings just as aspects of the social interaction in the clinical consultation alone, some studies show that the organisation of health care also influences patient-professional relationships. Organisational aspects of care can facilitate the development of a "relationship of trust" (Montori et al.,206, 31) by enabling the establishment of relational continuity and providing enough time for effective communication in consultations (Entwistle et al., 2008; Pooley et al., 2001). This is further supported by research into continuity of care which suggests that patients with diabetes who did not experience relational continuity also feel less involved in health care decisions (Naithani et al., 2006). In addition, research into type 2 diabetes patients' experiences of relational continuity and being treated as a whole person, observe that this improves trust and confidence health care providers and creates a perception of being cared for (Alazri et al., 2006; Naithani et al., 2006). This in turn made it easier for patients to raise sensitive or embarrassing topics and had the potential to improve patients 'adherence' to professional advice (Alazri et al., 2006; Naithani et al., 2006). However, Alazri et al. (2006) also notes that patients' views of the benefits of

continuity were tempered with concerns that it might lead to mis-diagnoses due to over-familiarity, and patients' experiences of continuity were related to the size of their general practice. So, the variation in general practice and changes in the organisation of diabetes care accelerated by the nGMS contract may also influence patients' experiences of relational continuity of care and involvement in diabetes treatment decisions. Moreover, as I will now discuss, changes in the organisation of care in themselves may be meaningful in informing patients' perceptions of their diabetes.

Interpretations of the organisation of care

In the late 1980s, Kinmonth et al. (1989) carried out a study exploring the introduction of structured care for non-insulin dependent diabetes into two English general practices (Kinmonth et al., 1989; Murphy et al., 1992). They found that patients preferred receiving care in general practice because they viewed GPs as having enough knowledge to care for their diabetes and considered them to be better communicators and more accessible than the hospital specialists (Kinmonth et al., 1989; Murphy et al., 1992).

More recent research has been carried out by Lawton et al. (2005b) at a time when the services in NHS Lothian were undergoing a major reorganisation, moving routine care (such as review appointments) for type 2 diabetes into primary care. This study suggests that for some people newly diagnosed with type 2 diabetes who are asymptomatic, the organisation of their care can be interpreted as an external indicator of the state of their condition (Lawton et al., 2005b). For example, since hospital care is associated with experts perceived to treat severe illness, receiving all their care within general practice or being discharged from hospital is, in some cases, interpreted by patients as a sign that their diabetes is not a particularly serious disease (Lawton et al., 2005b, 1427-1429). However, the authors go on to note that, over-time, established perceptions of the disease also inform preferences for health service delivery. For example, once a person considers their diabetes to be serious, they express a preference for care in a hospital clinic (Lawton et al., 2005b, 1430). Lawton et al. (2005b) conclude that, in the absence

of embodied experiences of illness, disease perceptions, expectations and experiences of health services are dynamically interacting.

However, this analysis focuses on changes in service organisation between hospital and general practice rather than the organisation of care in general practice itself. The study design also did not differentiate between the practices patients were registered at. Hence, Lawton et al. (2005b) were unable to observe whether differences in the organisation of care at the level of the general practice, and patients' relationships with particular professionals also influenced the perception and use of health service organisation as an external marker of disease progression. This is a particularly significant considering the reorganisation of general practice in response to the nGMS contract discussed above. Indeed, Lawton et al.'s (2009) recent follow up of their study four years on suggests that the particularities of care organisation in general practice was noted by patients and evaluated in relation to the perceived expertise of the professional providing care. Hence, a consideration of patients' interpretations of the organisation of diabetes care in general practice is a particularly important area for research which this thesis will take forward.

In addition to the meanings which Lawton et al. (2005b) show can be attached to being discharged from secondary care, in other articles they show that people with type 2 diabetes were optimistic about receiving their future diabetes care in general practice. This, they argue, is because patients view general practice as easily accessible and practice nurses, in particular, were identified as having strong communication skills (Lawton et al., 2005c). Interviewing the same people four years on, patients experiences of diabetes care in general practice had not met all of their hopes. Lawton et al. (2009) describe patients continuing to view general practice as convenient, and viewing their clinical reviews as "good enough", partly because they observed that their review appointments were quite standardised (Lawton et al., 2009,145). However, despite the value they placed on nurses' good communication skills, patients were concerned that a GP should also be involved and have the final say in treatment. In addition, Lawton et al. (2009) report that, when diabetes care was provided by a nominated GP or nurse who

was not usually involved in the patients' care, it was not experienced by patients as holistically integrated into their general practice care as a whole. Hence, patients' hopes of being able to receive diabetes care from a known and liked GP were not always met.

The ways in which care was apparently being organised in the practices in Lawton et al.'s (2009) study matches the general trends found in response to the nGMS contract and discussed in the previous section. However, as the people in this study were diagnosed after the introduction of the nGMS contract, and hence had no experience of diabetes care in general practice before its introduction, this study could not access the meanings patients might ascribe to organisational changes and the potentially increased standardisation of care prompted by the QOF. In addition, since Lawton et al. (2005a) have shown that patients draw on changes in the organisation of their care as an external indicator of their disease state, experiences of changes in the organisation of care within general practice warrant further investigation as factors shaping the illness experience.

Moving on.

In the above review I outlined two areas of literature which seem to rarely cross. The first focused on the apparently changing nature of clinical practice and the way in which health policy is implemented in differing ways depending on the context and professionals involved. The second focused on studies of patients' experiences of living with type 2 diabetes and argued that there is a need for further research which incorporates patients' experiences and interpretations of the health services they receive as part of their experience of living with, and perceptions of, type 2 diabetes.

From my perspective these two areas of study are inter-related and have the potential to be mutually informing. Hence, this thesis aims to further our understanding of how health policies relating to care for type 2 diabetes are interpreted and enacted by health professionals in differing primary care settings, and how this might influence patients' experiences and perceptions of the condition. With this in mind, this thesis will aim to address, and consider the relationships between two key research questions:

1. In what ways do health policies influence the organisation and provision of diabetes services in differing primary care contexts?
2. Do patients' perceptions and experiences of their primary care diabetes services influence the way they perceive and experience their condition, and if so, how?

How I went about collecting data to answer these questions is the topic of the next chapter, in which I outline my research methodology.

Chapter 3: Methodology

Introduction

This thesis seeks to explore and develop a better understanding of patients' and professionals' experiences of diabetes care. It aims to understand the ways in which health professionals interpret or give meaning to health policy and organise healthcare. It then explores the meanings patients associate with the healthcare they receive, and how they may (re)interpret their own health in light of those meanings. The research questions outlined in the literature review focus on "how", but aim to address some possibilities of "why", and can be broken down into sub-questions to guide the research design and analysis:

1. In what ways do health policies influence the organisation and provision of diabetes services in differing primary care contexts?

Health policy may not be the only influence on the organisation of diabetes services and hence in order to address this question I need to ask what else influences the organisation of care. I ask how health policies are interpreted by health professionals, why there might be variation, and explore whether this influences care provision.

2. Do patients' perceptions and experiences of their primary care diabetes services influence the way they perceive and experience their condition, and if so, how?

In order to address this question I need to know how patients' experience and perceive both their condition and their health care. If these vary I ask why, and consider whether there might be any relationship between their perceptions of their health care and their perceptions and experiences of their condition.

The exploratory nature of these questions calls for a qualitative and inductive approach (Britten et al., 1995; Bryman, 2004; Morse and Field, 1995). The way in which a researcher devises their research questions is likely to be partly determined by their

"existing ontological assumptions" (Bryman, 2004, 19); that is, the researcher's perspective on the "form and nature of reality and, therefore, what there is that can be known about it" (Guba and Lincoln, 1994, 108). A wide variety of perspectives are adopted in the social sciences ranging between the extremes of postmodernism and the hypothetical stance of positivism. Positivism assumes that social practices exist in an external, objective reality which can be ascertained through various standardised techniques of direct observation which do not affect that reality (Bryman, 2004). In contrast, postmodernists assert that all aspects of human culture are constituted in language, therefore, "there is *nothing knowable outside language*" (Fox, 1993, 6 emphasis in original). Hence, according to postmodernists, we can only study the discourses of power/ knowledge which are used to construct/ create reality as we know it.

Both of these extremes can be accused of reductionism. Positivism reduces the study of social practices to what can be assessed through the researcher's externally imposed categories and so negates the meanings employed by the social actors themselves (Silverman, 1995). In contrast, postmodernism, which is a form of strong social constructionism (Williams, 2006), reduces our experience of the world to that which is created through discourses of power. So, everything becomes social, and our embodied experience of the world becomes "little more than a fabrication" (Williams, 2006, 9).

The formulation and approach I have adopted in developing and addressing my research questions reflects my own ontological stance which has been influenced by my background in social anthropology and tries to understand perceptions and experiences of diabetes and its care from the perspective of the actors involved. My approach is inherently interpretivist and I would also locate myself within the "broad church" (Armstrong, 1997) of social constructionism, but adopt a "weaker" form than that of postmodernism. As I view it, the reality which we perceive and the knowledge that we can have of that reality, is socially and culturally constructed. However, unlike the postmodernist's position I do not suggest that nature can be reduced to cultural

discourse. Rather, I see nature (an external reality of some sort) and culture as mutually constituting and dynamically interacting. As Lock and Kaufert (2001) have illustrated in their cross-cultural study of menopause "it is appropriate to think of biology and culture as in a continuous feedback relationship of ongoing exchange, in which *both* are subject to variation" (Lock and Kaufert, 2001). This approach reflects other now well established flattenings of the dichotomy of nature/culture within anthropology (Franklin, 1997; Strathern, 1992; Bourdieu, 1990), the sociology of science (Latour, 1993; Latour, 2005), and strands within sociology of health and illness which have developed from a critical realist stance (Williams, 1999). My ontological position understands reality as constructing and constructed through culture, the cultural and the natural are mutually constituting with shifting boundaries and with neither being more 'real' than the other.

This approach, unlike that of postmodern reductions to discourse, leaves room to incorporate the embodied experience of illness whilst acknowledging that this experience is also culturally constructed. Our experience and knowledge of the world is only possible through our lived bodies. It is insufficient to focus on the meanings associated with illness alone. Illness has the very direct and pre-discursive effect of drawing attention to the "dys-appearing" body (Leder, 1990). "Bodies change in chronic illness" and are a central part of a person's experience of that illness (Kelly and Field, 1996, 247). As researchers we can only start to understand this by attempting to adopt the perspective of that person through their accounts of their experience of illness and its treatment. However, these accounts of experience, perceptions and actions are in themselves situated and constructed in reference to a particular social and cultural context.

The epistemological corollary of the above ontological stance is that the knowledge created through social research is constructed through the interaction of researcher and researched (Silverman, 1995). In addition, the reported results are the researcher's interpretation of the various interpretations of the social presented to her by those taking part in the study (Geertz, 1973). Part of the role of the researcher is to interpret within

the frame of a particular discipline, but these interpretations will also inevitably also be influenced by the researcher's pre-conceptions. These preconceptions are best dealt with by the researcher being aware of them and considering and discussing other perspectives. I have already stated my ontological position and that this has been influenced by my degree in social anthropology. Also, from a personal perspective, I spent a large amount of my childhood in and around my parent's general practice in England and was, to an extent, socialized in an approach to general practice which idealised continuity of care and mutual social knowledge between patient and professional. These aspects of my own identity will inevitably have informed my approach and analysis.

A multiple case study research design

Multiple case study designs are considered appropriate for furthering our understanding of a particular phenomenon or program (Stake, 2006 refers to this as a "Quintain") and "its commonality and differences across manifestations" (Stake, 2006, 40).

> Each case is studied to gain understanding of that particular entity as it is situated. The Quintain is studied in some of its situations. It is supposed that the complex meanings of the Quintain are understood differently and better because of the particular activity and contexts of each case. (Stake, 2006, 40).

The research questions above aim to create a linked understanding of the organisation and experience of diabetes care and the meanings associated with that experience. Supported by my literature review I assumed that multiple factors may influence the organisation of diabetes care, for example a general practice's location, size and ethos. I am interested in knowing how and why diabetes care is organised as it is in particular contextual situations and the consequences of this for patients' experiences of care. This is so that, through a cross-case comparison, I can better understand the links or commonalities between organising diabetes care and patients' experience and interpretations of that care. Hence I have adopted what Stake has termed an "instrumental" multiple case study approach (Stake, 2006, 8), aiming to understand the

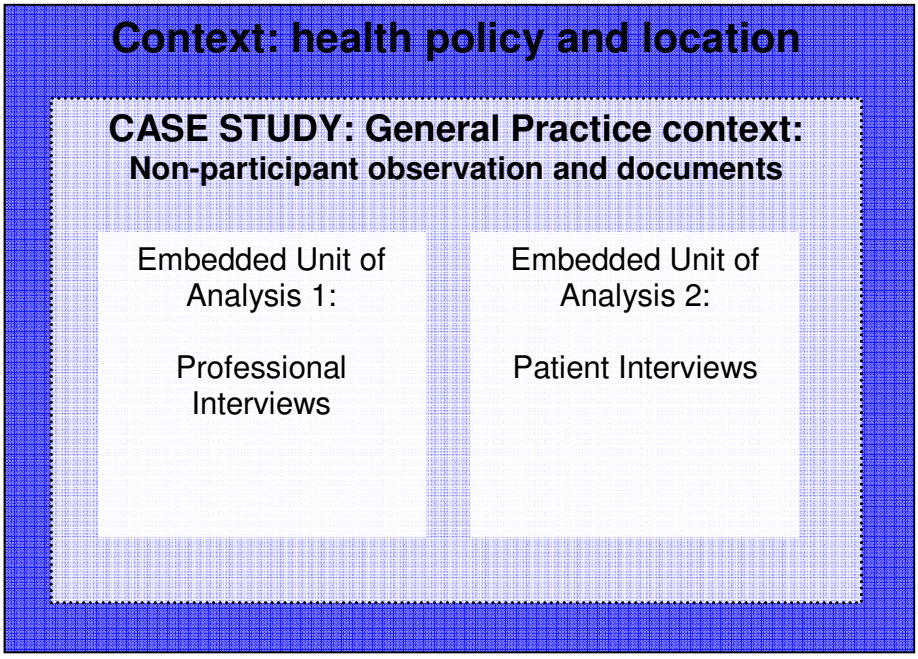
general phenomenon of delivering diabetes care and its meanings, rather than a specific case for it's own sake.

A case is a "bounded system", a "specific, complex, functioning thing" (Stake, 1995, 2). In this research, each case includes (what I have termed) a 'primary care diabetes team' and patients cared for by this team. Each case is studied in light of its "context or environment" which may influence the activities within the case, hence making the boundaries between case and context blur at times (Stake, 2006). In this study the context included factors such as: patients' and health professionals' wider lives and biographies, their previous experiences of receiving or providing diabetes and other health care, national health policy, technologies, access to secondary care, and the historical and geographical context of the primary care 'team' and general practice.

In a multiple case study the overall research questions provide a "conceptual infrastructure" (Stake, 2006, 9) or focus which guides the study. However, within each particular case, questions, or emic "issues", particular to that case may arise, and so the research moves back and forth from focusing on each case to the concerns of the "Quintain" (Stake, 2006, 9). For example, whilst one of my overall research question asked in what ways health policies influence the organisation of diabetes care, I found that in one case study, the ongoing and historical referral patterns between primary and secondary care were viewed by the professionals involved as having a much more significant influence on service organisation. This "emic" issue (Stake, 2006, 10) then drew my attention to the role of primary-secondary care relationships across the cases and I found that this emerged as an important factor across all three cases, although less explicitly emphasised.

Each of my case studies contained multiple subsections, the various actors involved and sources of data such as local clinical guideline documents. These constitute what Yin terms "embedded units of analysis", and the diagram below, adapted from Yin (2009, 46), illustrates the research design of each case.

Embedded Case Study Design



Choosing data collection strategies

Data collection in each case study involved semi-structured interviews, non-participant observation, and some comparative analysis of health policy documents and clinical guidelines. These forms of data collection have often been combined in a mutually informing iterative process in case studies (Stake, 2006, 29) and ethnographic fieldwork. In this sense, data collection for each case study is similar to a "mini" or "focused ethnography" (Morse and Field, 1995,155). In this section I will explain my rationale for choosing each of these methods before going on to outline how they were used together in order to develop an understanding of each case as a whole.

Semi-structured Interviews

Semi- structured interviews are the best approach to use to gain an insight into the individual perspectives of participants (Patton, 2002, 341). Individual interviews also enable the researcher to ask about past events and the participant's reactions to these. As Patton (2002, 341) put it: "we interview to find out what is in and on someone else's mind, to gather their stories".

Since I was interested in hearing patients' personal accounts of their experiences of receiving care and living with type 2 diabetes, interviews seemed the most appropriate strategy. These personal accounts would be difficult to access by other means. For example, in the early stages of research design I considered using focus groups. However, whilst focus groups are useful in gaining an insight into how a consensus view of a phenomenon might be formed through social interaction they would have not enabled me to access individual perceptions and experiences (Kitzinger, 1995; Patton, 2002). Focus groups are inappropriate for researching individual patients' experiences of their chronic illness and care. In addition, confidentiality was important so that patients could speak freely about their health services without fear of it influencing the care they received. Similarly, I judged focus groups to be inappropriate for accessing individual

health professionals' perspectives on the factors influencing the organisation of diabetes care.

I chose a semi-structured approach to the interviews in order to focus the interview on the interests of this research whilst allowing the interviewees to present their own way of seeing the world and raise issues which they considered important to the topics being discussed (Silverman, 1995, 95). This reflects the inductive approach of this research which aimed to learn what aspects of receiving or providing care and living with diabetes were presented as important by the participants rather than relying on the pre-ordained concepts of the researcher (Patton, 2002, 494). The semi-structured approach also meant that the interviewee had greater control over discussing what they perceived as important about their experience of diabetes an its care. I also thought that by giving greater control to the interviewee our discussion might be less likely to cause distress. Interviews formed the primary data source for this study but were contextualised and informed by observation and documentary analysis.

Non-Participant Observation

The observational component of the research aimed to provide a more holistic understanding of each case study which informed the areas explored in interviews and situated my understanding of the interview data within the context of the general practice (Patton, 2002; Silverman, 1995, 42). I decided to focus my observations on areas of the practice which I anticipated would be important in the organisation of diabetes care appointments, the introduction of health policies into the practice, and the coordination of care amongst the multiple health professionals involved. This meant that I focused on reception and administration areas, practice meetings, and any staff meetings concerning diabetes care. The exact areas included depended on the day to day structure of work within each practice. In these areas I aimed to record the various steps which were gone through to implement policies and arrange review appointments and the barriers and facilitators which were met in each practice along the way.

The observations I made at each case study were also directed by what I was being told in interviews with patients and professionals so, interviews and observations were mutually informing in an iterative manner. Concepts taken from one approach to data collection were confirmed and developed through another form, in a sense, 'triangulating' tentative findings as the research progressed (Stake, 2006, 37). This also meant that I also concurrently carried out some tentative analysis, developing concepts which guided more data collection in an iterative manner as suggested by proponents of grounded theory (Glaser and Strauss, 1967).

The degree of participation possible and appropriate is closely associated with the nature of the study and the various levels of participation in observational research exist on a continuum from being a complete participant to being a complete observer (Gold, 1958; Hammersley and Atkinson, 1995; Patton, 2002). Like many researchers the observational role which I adopted for was somewhere in-between these extremes (Hammersley and Atkinson, 1995, 107). My observation was participatory in the sense that I would interact and attempt to establish a rapport with the practice staff. Conversations with staff during observation were important in checking I did not misinterpret my observations. However, I did not intend to adopt any existing role within the case studies and hence was not a full participant.

The length of time which observation should be conducted depends on its purpose (Patton, 2002, 275). The information which I planned to gather through observation aimed to provide a better understanding of the organisation of diabetes care within each practice and inform some topics pursued in interviews. The observation was focused on specific areas of each case study and hence the amount of observation required was limited in this way. Moreover, the data collected through observations was to be analysed in collaboration with the other forms of data within each case study. Hence, I decided that every working day for two weeks would be a sufficient length of time to become familiar with the organisational strategies within the practices and establish a rapport with the staff involved and record the way in which they seemed to interact to

coordinate care. This length of time was also shaped by the pragmatics of carrying out the case studies in the time available.

In addition to the data from interviews and observations I collected copies of certain official documents relevant to informing my understanding of the context or organisation of diabetes care in each practice. These included national policy documents such as *Partnership for Care* (Scottish Executive, 2003), the *Scottish Diabetes Framework* (2002), *Diabetes Action Plan* (2006) and the nGMS contract (2004, 2006). However, they also included documents such as local clinical guidelines and general practice protocols which were referred to by professionals in their interviews. Data on local MCNs was also collected from their websites.

Whilst I have presented the policy context in a descriptive manner in the introduction to this thesis, in my analysis I will approach these documents as socially and culturally constructed artefacts. In order to understand the relationship between these policy documents and the care provided in each case study context it was essential that I was aware of both the content of these documents and the implicit assumptions they carry about type 2 diabetes and the social roles of patient and health professional in managing this condition (Abbott et al., 2004; Jupp and Norris, 1993).

Triangulation

Yin suggests that case studies should draw on multiple sources of "evidence" (Yin, 2009, 116). However, the different sources of data used in this study were not generally triangulated to corroborate the 'validity' of an external 'fact' or reality in the manner suggested by Yin (2009, 116). Rather, these data sources were both collected and analysed in a complementary manner. Data were compared and contrasted in order to further my understanding and gain assurance that I had not misinterpreted my data both within each individual case study and in the cross-case analysis (Stake, 2006, 35). As Hammersley and Atkinson have put it: "triangulation is a matter not of checking whether

data are valid, but of discovering which inferences from those data are valid" (Hammersley and Atkinson, 1995, 232).

Data from the differing sources were used in collaboration to create a more complete understanding of particular aspects of the case(s) as a whole (Silverman, 1995, 157). For example, the findings which will be presented in chapter four draw on data from both observations and professional interviews to create an overview of the approach or ethos of each case study general practice. Similarly, data from interviews with patients in each case study were interpreted and analysed within the context of information drawn from other aspects of that case, i.e. observational data and professional interviews. In addition, interviews with several patients at each practice enabled commonalities and differences in experience to be identified and explained. This furthered my understanding and enabled me to check my interpretations of patients' experiences at each case study as a whole. I also gave attention to suggesting explanations for exceptional cases, those whose accounts differed notably from other patients at the practice. As Dingwall has pointed out, the sociologist does not aim to "adjudicate between participants' competing versions but to understand the situated work they do" (Dingwall, 1981 as cited by Silverman, 1995, 158).

In the next section I will go on to outline the selection of case studies and professionals and patients to be recruited in each case.

Case study practices, professionals and patients

Choosing Case Studies

I chose to purposively sample case study general practices which might be expected to show variation in the way they organised their diabetes care but could be expected to be influenced by the Scottish Diabetes Framework and nGMS contract. In order to identify practices which would meet these criteria, I first chose to sample within two Health Boards which had performed to differing levels against Quality Improvement Scotland's

clinical standards for diabetes care (NHS Quality Improvement Scotland, 2004a; 2004b; 2004c; 2007a; 2007b; 2007c). Health Board A achieved approximately 30 percent of the QIS standards for diabetes care in 2004 whilst Health Board B had achieved approximately 70 percent of these standards (ibid). This implied that the organisation of care within these two Health Boards might be quite different.

Diabetes care in primary care is not limited to general practice but incorporates various other professionals working within the community. I anticipated that urban and rural primary care might organise their diabetes services quite differently because the availability and waiting times for allied health professionals may vary depending on the Health Board and the rural or urban location (Rural Access Action Team, 2005; The Remote and Rural Steering group, 2008). Also a general practice's proximity to secondary care diabetes centres may affect the coordination of care and the likelihood of referrals to diabetes specialists. Hence, a second factor in selecting Health Boards to sample within was that they contained many general practices in both rural and urban areas.

Having identified which Health Boards I would recruit practices within, I then went on to identify practices which might be expected to have their diabetes care influenced by both the Scottish Diabetes Framework (2001) and the Quality and Outcomes Framework (QOF) in the nGMS contract (2004/2006). Hence I chose to sample practices contracted through the nGMS contract which were participating in the diabetes targets incorporated in QOF. I then chose to invite practices on the basis of their urban/rural location. In order to do this I consulted the Scottish Executive's Urban/Rural classification of practices (see appendix X) to select some located in urban areas (categories one and two) and some in rural areas (categories seven and eight) to invite into the study (ISD Scotland, 2006b).

Choosing practices on the basis of differing levels of deprivation was also considered as a basis for selection as these might also be expected to demonstrate different

organisations of care and reflect differing pressures on the diabetes team as more deprived areas tend to have higher rates of diabetes (Scottish Diabetes Survey Monitoring Group, 2008). However, I preferred to sample on an urban/rural basis because I anticipated this would influence the organisation of care with professionals based outwith each general practice in addition to the organisation within the practice. For example, it would be possible to have a practice in a deprived area and one in an affluent area with access to the same allied health professionals and able to refer to the same secondary care centre with equal ease. So, the organisations of the 'primary care diabetes team' might be expected to be more similar in affluent and deprived practices, than in rural and urban practices. Whether this is actually the case could be explored in future research but this thesis progressed on the assumption that this was likely and that selecting on an urban/rural basis would show sufficient variation to address the research questions. Hence, potential case study practices paid under the nGMS contract were then identified on the basis of their urban/rural location within two Health Boards using publically available data from ISD Scotland (ISD Scotland, 2006a; 2006b).

I originally elected to carry out four case studies, one in a rural location and one in an urban area in two Health Boards. This was decided on the basis that four case studies would be enough to show variation in the organisation of care and hence provide enough data to develop an understanding of reasons for, and consequences of, this variation (Yin, 2009,54). However, as data collection progressed, it became clear that the first three practices recruited demonstrated sufficient variation to address my research questions. Moreover, the quantity of data associated with each case study meant that it would not have been pragmatic to continue with four case studies. Hence, the research design was altered and I stopped recruitment after three cases.

Selection of patients and professionals in each case study

In each case study I aimed to interview all those health professionals and administrative staff who made up the local 'primary care diabetes team'. However, I expected this to vary between the case studies, so I asked those professionals based within each general

practice and involved in providing the practice's diabetes review appointments to define what they would consider their 'primary care diabetes team'. This meant that the sample included the professionals that the participants themselves considered relevant rather than imposing my own external categories. This sample was further added to in an iterative manner if patients named another community based professional they considered part of their diabetes care, or if during observation professionals highlighted that someone had been initially forgotten who was a key part of the 'diabetes team'. Interestingly, at all three practices professionals thought that it was important to also interview one GP who was not involved in diabetes care. This, they suggested, would illustrate how diabetes care was separated out from everyday general practice work, and the increasing specialisation of general practice. I agreed to interview these GPs as this aspect of diabetes care organisation seemed important to those involved, and because these interviews would also enable me to develop a more rounded understanding of the ethos of each general practice.

Patients with type 2 diabetes registered at each of the case study practices were invited to interview on the basis of the following criteria:

- They were over 18 years old and adults able to give informed consent.
- They had been diagnosed with type 2 diabetes over five years earlier and so would have been receiving care for their condition both before and after the introduction of the Scottish Diabetes Framework (2001) and nGMS contract (2004). They would therefore be able to reflect on any changes which had occurred in the organisation of their care which may have resulted from these policy instruments.
- They were receiving their annual review appointment and the majority of care for their diabetes in primary care at the time of the research
- The GP involved with their care considered them mentally and physically able to discuss their condition with me and to give informed consent.

- They had received an appointment for their diabetes in the last twelve months and might be expected to be able to recall at least one interaction with the health services for their diabetes.

I decided to interview eight patients at each case study practice. The purpose of the patient interviews was to gather a range of accounts of receiving diabetes care and to consider how this was related to people's perceptions of their condition. Whilst eight is too small a number of interviews to be expected to reach a point of saturation at each of the case studies the interview data did not stand alone. Accounts of receiving care, and how patients' attributed meaning to these, were analysed in relation to each case study as a whole, and themes were developed by analysing across the three cases in their entirety, as I will explain in greater detail below. Eight patients was considered enough to gain a range of perspectives on the receipt of diabetes care and its meaning without being so many as to hinder a detailed analysis of each case and across the cases.

Recruitment

Before recruitment could begin my research proposal was approved by the Multi-Centre Research Ethics Committee for Scotland (MREC) and the Research and Development (RandD) departments of the two participating Health Boards. These Health Boards will be referred to as 'Board A' and 'Board B' in order to maintain the anonymity of the practices taking part.

Recruitment of Case Study General Practices

Recruitment of practices was based on the sampling criteria outlined above. I planned to recruit practices with the help of Scottish Practices and Professionals Involved in Research (SPPIRe)[6] who agreed to forward my letter of invitation and to reimburse

[6] Now known as the Scottish Primary Care Research Network (SPCRN)

practices for their time. This amounted to a few hundred pounds for each practice and was more of a token gesture of thanks than a major financial incentive to take part. However, recruitment did not follow this plan.

Before I submitted my ethics form to the NHS Ethics committee I e-mailed a copy of the proposed study protocol to the managers of the Health Board's diabetes Managed Clinical Networks inviting them to comment on the proposed project. This was done to try and assure that the research seemed relevant to them and so that they could highlight any difficulties I might face conducting research in their area. They expressed no concerns with the project and gave no other feedback. However, without my consent, the diabetes MCN manager for Board A forwarded my e-mail to all of the practices in his area. I only discovered this when I received e-mails from two practices expressing an interest in participating. As they fitted my sampling criteria I agreed to them taking part once ethical approval was given. One of these practices was a remote and rural practice and the other based in a village half an hour from a large urban centre. In addition, another practice heard of my research through personal contacts and expressed an interest in taking part. This third practice fitted my criteria of an urban case study in Board B and so I also agreed to their participation. The practices were given pseudonyms in order to maintain their anonymity. The remote and rural practice is 'Silvenea Island Surgery', the one in a rural village is 'Strathfinella Practice' and the urban practice is 'Corryhabbie Medical Centre'.

The GPs who volunteered their practices to take part in the study all gave different reasons for wanting to participate, and it is worth bearing in mind their own agendas when reading the analysis. At Silvenea the GP who contacted me told me that they wanted to take part because they felt that the benefits of remote and rural general practice in general were being overlooked and undervalued by quantitative measures of practice performance. At Strathfinella, the GP and practice nurse said the practice wanted to take part because they wanted feedback on what their patients thought of their diabetes service as they felt that the patient satisfaction questionnaire included in the

nGMS contract did not give the kind of in-depth information they wanted. Finally, the GP from Corryhabbie said that they were interested in taking part because they saw themselves as innovative and wanted to be involved in research.

The table below summarises details of these practices. However, details such as list size and QOF scores are given as approximate values to maintain the practice's anonymity.

Table 1: The three case study practices

	Silvenea (remote and rural case)	**Corryhabbie (Urban case)**	**Strathfinella (Semi-rural case)**
Modal Scottish Executive Urban/ Rural Classification based on number of registered patients in each category (ISD Scotland, 2006b). See Appendix X	8: Very Remote and Rural. Two percent of this practice's population lived in a very remote small town (Cat 5).	2: Urban area settlement. However, over a third of this practice's population lived in accessible rural settlements (Cat. 6)	7: Remote and rural settlement. However, nearly a quarter of patients at this practice lived in an accessible small town (Cat 3) and a third lived in an accessible rural settlement.
Scottish Index of Multiple Deprivation (1=least deprived; 5=most deprived) (ISD Scotland, 2006c)	3	2	3
Approximate List Size (ISD, Scotland, 2006a)	1,000	16,000	3,000
No. with diabetes (ISD Scotland, 2006a)	30	600	100
% achievement of QOF points for diabetes (ISD Scotland, 2006a)	100	99	98
No. GP partners (All GPs)	1 full time 1 part time (2 days a week)	14 most of whom are part-time	2 full time 2 Salaried GPs
Other staff employed by or based at the practice.	1 practice nurse (4 hrs a week) 1 receptionist part-time 1 practice manager/ receptionist. 1 Health care assistant part time. 2 district nurses based at the practice, one is there fulltime, the other is peripatetic	10 practice or specialist nurses 1 phlebotomist 23 administrative and reception staff. 1 practice manager 1 assistant practice manager. 7 District nurses in addition to midwifery and health visitor teams.	2 practice nurses 1 health care assistant 1 practice manager 5 reception/ administrative staff The district nurses are based at another practice in the area.
Percentage of practice population in age ranges:	0-40 34% 41- 60 34% 61-80 27% 81+ 5%	0-40 50% 41- 60 29% 61-80 16% 81+ 4%	0-40 54% 41-60 25% 61- 80 18% 81+ 3%

Recruitment of the 'primary care diabetes team' for interviews

I arranged introductory meetings to further explain the study and discuss any concerns with the staff at each practice before commencing fieldwork. Practicalities such as potential dates for my fieldwork and where I could stay were also discussed at this meeting. I also asked the various staff at this meeting which included those most central to organising diabetes care at the practice to outline who they would define as their 'primary care diabetes team'. On returning from this meeting I sent a letter to all professionals named inviting them to be interviewed and explaining the observational component of the research. This letter also included a response slip and return envelope so that they could opt to be interviewed and could opt out of the observational component of the research confidentially. I intended to add to this initial sample if other professionals emerged as part of the 'team' over the course of my observations and interviews. However, only at Corryhabbie (urban) was the initial sample added to, as district nurses at that practice who were not initially named approached me and requested interviews about their role in diabetes care. Interestingly, only at Silvenea were district nurses named by professionals or patients as part of diabetes care provision and at Strathfinella the district nurse was not named as part of diabetes care.

The initial outline of who was considered part of the primary care diabetes team was also a useful piece of data as it made the differences in the organisation of care at each practice apparent from an early stage. In line with the inductive approach of the study and following the principles of concurrent data collection and analysis, the questions arising from this original outline of the 'diabetes team' informed subsequent lines of inquiry. For example, they raised important questions such as: Why was it when I asked the staff at Silvenea (remote and rural) to outline who was involved with diabetes care at a primary care level they did not include a dietician? Why, at Corryhabbie (urban), was I warned from the outset that the organisation of the diabetes service had caused tensions between the professionals within the practice and with secondary care?

At none of the three practices did any professionals decline to be interviewed, but one person chose not to be audio-recorded. Personal contact has been shown to improve response rates of patients in other areas of health service research (Sitzia and Wood, 1998). Hence, the high response rate of professionals might be attributed to my personal contact with some of these professionals at the initial meeting and their subsequent advocacy of my research to other professionals based outwith the practice. An outline of which professionals were interviewed in each case is given in the table below.

Table 2: Professionals interviewed at each case study

Case Study General Practice	Pseudonym	Professional Role
Silvenea (remote and rural)		
1.	Dr. James Harrison	GP diabetes lead
2.	Dr. Eilidh Crawford	Part-time GP
3.	Kiera	Diabetes Specialist Nurse (DSN)
4.	Allan	Podiatrist
5.	Susie	District Nurse
6.	Louise	Health Care Assistant
7.	Samantha	District Nurse
8.	Jenny	Practice Nurse
Corryhabbie (urban)		
9.	Dr. Christina Andrews	GP diabetes lead
10.	Vicki	Nurse diabetes lead
11.	Dr. John Shore	GP
12.	Patricia	DSN
13.	Jane	Dietician
14.	Robert, Alice and Jennet	Podiatrists
15.	Holly	DN
16.	Susanna	Diabetes Administrator
17.	Pat	Practice Nurse cardiac lead
Strathfinella (rural village)		
18.	Dr. Rosalind Scott	GP diabetes lead
19.	Erica	Practice Nurse diabetes lead
20.	Dr. Connor MacLeod	GP
21.	Dr. Michael Gion	GP diabetes lead
22.	Sarah	DSN
23.	Kirsten	Dietician
24.	Liz	Podiatrist
25.	Annemarie	Receptionist and diabetes admin
26.	Claire	Practice Manager

As can be seen from the table above whilst the composition of professionals in each case varied slightly, there were eight or nine interviewed in each case. At Strathfinella the practice manager was interviewed as she was involved with ensuring that the various aspects of the nGMS contract were met and was the person through whom all external communication, such as the publication of new local or national guidelines or national service frameworks, passed. At Silvenea the practice manager was interviewed and notes taken during observation. At Corryhabbie the practice manager was unavailable for interview but the administrator of the diabetes clinic was interviewed.

The pseudonyms used for the health professionals reflect the way in which the professionals were referred to by both patients and their colleagues. GPs at all three practices were referred to by either their first name or surname or both so, for simplicity I have referred to them by their surnames. In contrast nurses and other clinicians and staff tended to be referred to by their first name only and I have reflected this in my pseudonyms. Interestingly, at the more rural practices (Silvenea and Strathfinella) it was more common for patients to refer to their GP by their first name than at the urban practice, Corryhabbie.

Recruitment for participant observation

All staff at the practices were provided with an information sheet about the project and asked to return a response slip to me if they wanted to opt out of observations (see appendices IV and VII). If someone stated that they did not want to be included in the observational component of the research I planned to simply not make any notes which included them. I sought verbal consent for my observations and repeated this several times making it clear that I was taking notes. The NHS ethics committee approved this approach, and at Silvenea and Strathfinella no one declined to take part in the observation.

At Corryhabbie there was some misunderstanding in the execution of this process. At the start of my observations all of the professionals I had invited to interview had

returned response slips opting in and no one had mailed or left a response slip for me opting out of the observations. The lead GP for diabetes reassured me that everyone in the practice had been told that my research was taking place, had seen information slips, and not opted out. So, I started field work introducing myself and the research to everyone I spoke to and going on to ask them about what they were doing, about the practice and the organisation of care. However, on the third day the GP came told me that some of the reception staff wanted to know why I had been questioning and taking notes about administration of the nGMS contract etc. It emerged that because the information sheet had been headed as being for "health professionals" it had not been passed on to reception and administrative staff. Evidently there had been a misunderstanding. I immediately produced multiple information sheets which I handed out, posted on notice boards in the reception area and left in the coffee room. I also made a point of making it very clear to everyone I spoke to that I was doing research and that they could opt out of the observational component if they wanted. There were no further misunderstandings and research continued. I was also more careful to make sure that everyone knew I was doing research and observing everyday life in the practice in the next case study.

Recruitment of people with type 2 diabetes

I decided that patients taking part in my study should remain unknown to the health professionals so that patients could speak freely about their experiences of care without fear of it influencing their future care. However, for reasons of confidentiality and legality I could not be given the names and addresses of patients. So, I asked each practice to forward my letter of invitation, information sheet and response form (appendices II, III and VI) with a stamped addressed envelope to at least 20 patients meeting my sampling criteria. Patients then opted into the study by returning the response slip directly to me. In this way the practice would not know which patients opted in and which did not. Also as previous research (Pooley, 1999; Sitzia and Wood, 1998) in related areas has reported response rates of around 80% for similar face to face

interview research, I anticipated that at least eight would respond if I invited 20 patients to take part.

At Corryhabbie the professionals decided they wanted to invite 23 patients just to make sure that I had enough responses, 16 people (70%) responded. At Silvenea practice only 16 patients met my sampling criteria, however, as this would still only require a response rate of 50% I decided to proceed with recruitment. Twelve out of 16 patients (75%) responded. At Strathfinella only eight out of 20 patients (40%) responded and I could not get in touch with one of these patients so only seven were interviewed. At Corryhabbie and Silvenea where more than eight people responded I tried to select people of a range of ages and equal numbers of male and female for interview, this was so a range of perspectives on the experience of diabetes and its care would be represented. Selection was also constrained by who could be contacted by telephone before I started fieldwork to arrange a date and time for interview.

The respondents were all White British or White Scottish reflecting the ethnic makeup of the two Health Boards involved which both have a population which is over 95% White British or Scottish (Scotland's Census Results Online, 2001). Other characteristics of the patient sample are given in the tables below.

Table 3: Patient Sample by gender

Case Study General Practice	Gender	
	Male	Female
Silvenea (remote and rural)	3	5
Corryhabbie (urban)	4	4
Strathfinella (rural village)	3	4

Table 4: Patient sample by age at interview

Case Study General Practice	Age at interview (years)					
	31-40	41-50	51-60	61-70	71-80	80+
Silvenea (remote and rural)	0	0	1	2	3	2
Corryhabbie (urban)	0	1	1	1	3	2
Strathfinella (rural village)	1	0	3	1	2	0

Across all three case studies around 70% of my sample were over 60. This is not surprising as the prevalence of type 2 diabetes increases with age, with the peak age for

onset in developed countries being between 60-70 years (Williams and Pickup, 2004). However, there is also some variation in the ages of the patients interviewed within each practice, with the sample at Corryhabbie and Silvenea being more similar to each other, than to the sample at Strathfinella. This may have skewed my findings slightly.

Table 5: Patient sample by length of time since diagnosis:

Case Study General Practice	Length of time since diagnosis (years)			
	5- 10	11-20	21-30	30+
Silvenea (remote and rural)	6	1	0	1
Corryhabbie (urban)	2	2	1	3
Strathfinella (rural village)	5	1	2	0

The majority of patients who took part had been diagnosed in the last ten years, with 71% of the sample being diagnosed in the past twenty years. All patients had received care for diabetes long enough to note any changes brought about by the nGMS contract and Scottish Diabetes Framework. However, the changes themselves may have been viewed differently by those more experienced patients who may have seen many changes in the health service since they were diagnosed. Indeed, one man interviewed told me that he had seen many changes since he was diagnosed before the establishment of the NHS. This was borne in mind in the analysis.

Table 6: Patient Sample by Standard Occupational Classification

Case Study General Practice	Standard Occupational Classification (2000)		
	1-3	4-6	7-9
Silvenea (remote and rural)	5	3	0
Corryhabbie (urban)	6	1	1
Strathfinella (rural village)	3	3	1

Standard occupational classification has been used here as a proxy of socio-economic status (Office for National Statistics, 2000; 2008). Occupational classifications one to three include managers, senior officials, professionals and associate professionals. Classifications four to six include administrative occupations, skilled trades and personal service occupations, and categories seven to nine include sales and customer service occupations, process, plant, and machine operatives and non-skilled occupations. As one can see the majority of the patients fell into classes one to six, reflecting the relative

affluence of the practice locations. There was not a large variation between the practices in the social occupations of those interviewed, although those at Corryhabbie were skewed more towards groups 1-3 than at the other practices.

As discussed in the literature review, both the length of time since a person was diagnosed with diabetes and their age at diagnosis have been shown to influence their perspective of their condition and their expectations of their health care (Lawton et al., 2008; Savoca et al., 2004). In addition socio-economic status has been shown to be a significant factor in the effective adoption of regimens of self care and in interactions with the health services (Drummond and Mason, 1990; Hunt and Arar, 2001; Say et al., 2006).

Data Collection

As noted above data collection and analysis were iterative processes developing concepts which not only informed the data collected over the time spent at each case study, but also sensitising the researcher to potentially significant topics across the case studies. In this section I will briefly outline the process of collecting data through interviews and observations, which took place between April and September 2007, and reflect on the difficulties I met.

Interviews

Interviews with patients were usually conducted in their homes but a few preferred to be interviewed at the general practice and a room was provided for this purpose at all three practices. All interviews with professionals were conducted in their place of work. Interviews lasted between 50 minutes and two hours with the exception of one interview where the professional was only available for half an hour.

Before commencing each interview I discussed the project with the interviewee and addressed any questions they had. I also explained how the data would be used and that they would remain anonymous and what they told me was confidential. Only then did I

ask them to sign a consent form. This initial conversation served to put the interviewee at ease, and helped established a rapport which I believe improved the subsequent interview as most people gave extended responses to my questions. This introductory conversation was longer with patients and with professionals not based at the practice, as professionals based at the practice had the opportunity to talk to me before the interview and a rapport had already been established through my observations. One GP commented that she felt she could be much more open and honest in her interview than she thought would otherwise have been the case because she felt she had got "to know and trust" me over the course of the observation. Professionals based outwith the practice tended to be more tentative about discussing sensitive issues; for example, any tensions with the case study general practice in question. However, these professionals often became more open when they realised that I had been 'based' at the practice, but this might have meant they were less willing to be critical of the professional colleagues I knew. Moreover, the maintenance of confidentiality has been difficult as professionals' roles sometimes make them identifiable to other participants in this study. Hence, when something potentially controversial is presented in the thesis I have deliberately chosen to obscure the exact source of that opinion.

As planned, I went into interviews with topic guides (shown in appendices VIII and IX) developed on the basis of my literature review and research questions. These guides were also modified in light of emerging concepts and non-participant observations in each case study. I also tried to direct the conversation in as natural a manner as possible in order to maintain the flow of conversation, develop a rapport and enable the interviewee to speak freely about what was important to them (Rubin and Rubin, 1995). In interviews with professionals I started by asking them to outline their work in general and the role they played in relation to diabetes care. We then went on to discuss topics such as how diabetes care came to be organised in the way it was at each practice.

In most interviews with patients, the interviewee took the lead telling their story from causation to present day. Topics discussed included, but were not limited to, questions

about how they had found out they had diabetes and how they had learned to manage their condition. I then went on to ask about their experiences of health care for diabetes. For example, I asked whether they felt involved in treatment decisions, and whether they felt they would like to receive more information about their diabetes and their blood test results, and why.

In a few interviews patients asked whether their partner could be present. I agreed to this and asked their partner to sign a consent form. This obviously impacted on the data formed in these interviews as the social interaction between three people in the interview was different to interviews where there was just one interviewee. However, people live in a social setting and if they consider their partners views to be important in their presentation of living with and receiving care for diabetes, then it seemed appropriate to include them in the interview as requested.

To enable an in-depth thematic analysis all interviews were transcribed verbatim by me and a paid professional audio-typist. These transcripts noted hesitations, emphasis and interjections in order to enable better understanding of the full meaning of what was said. All transcripts not completed by myself were also checked against the audio recordings. However, quotations in the chapters that follow have been simplified by removing interjections, hesitations and repeated information in order to ease reading. Where these modifications have been made this is indicated by an ellipsis.

Observation

The first two days of the two week period were spent observing the practice to develop a basic understanding of the organisation and the diabetes service at that case study and the practice as a whole. After these first two days I went for a few hours each day conducting interviews with patients and health professionals.

My observations involved taking notes of the conversations I had with administrative staff as they explained to me what they were doing and discussed the organisation of

diabetes care. These conversations also often turned to discuss the effects which the nGMS contract had had upon their daily work and the pros and cons of the changes it had brought about. For example, at Corryhabbie the data entry staff felt strongly that the dual effects of the nGMS contract and their new computer system meant that fewer patients now "dropped through the net" because it meant that systems for arranging appointments such as the diabetes review were now more effective. At other practices these discussions also yielded important data about the subtleties of arranging review appointments. For example, at Strathfinella only by going through her working practices with the receptionist who organised diabetes review appointments did it become apparent that she knew personal details about most of the patients and used this knowledge to arrange their appointments at a time she imagined would be convenient to them. In addition, I observed the way in which the staff at each practice interacted with one another. For example, at Corryhabbie I noted that the different staff (nurses, GPs, reception staff) tended not to mingle during their breaks. Within the staff room there seemed to be a pattern of place. GPs sat to socialise and discuss patients in one particular area of the staff room and the other staff sat elsewhere and during the period I was there did not once sit in the GPs' area. If a nurse wanted to discuss a patient with a GP in the staff room at lunch time they would wait on the edge of the 'GP area' to be acknowledged and invited to speak, rather than just sitting down with them. This contrasted starkly with the way in which the professionals interacted at the other case study practices. Observations of the staff room and inter-professional interaction also highlighted that, within all three cases, the coordination of care often seemed to be enhanced through informal discussions about patients.

At Strathfinella the nurse and GP reviewed patients' diabetes care in separate meetings to the patient consultation and so, I also sat in on these meetings and took notes of their conversation paying particular attention to what informed their clinical decision making. I also recorded how the building was laid out, thinking that the physical organisation of the building might be related to the social interactions between staff and hence the coordination of care (Lefebvre, 1998; Yanow, 2007). All observations were recorded in

a notebook and typed up into a word document each evening so that emergent concepts could be identified and pursued further in the next day of observation and interviews. In my analysis, observation was used as data in its own right, but also enabled a more subtly informed and contextualised analysis of interview data to develop a detailed understanding of each case (Patton, 2002; Yin, 2009).

As a non-participant observer at each of the three practices I was positioned in a slightly different role by the people at the practice. At Silvenea I seemed to be viewed by the GPs and administrative staff and the district nurse as someone to chat to when things were quiet and everyone gathered in the reception area to catch up. In reception I was also treated as an extra pair of hands to find patients' A4 notes and make tea. Similarly, at Strathfinella it was common for the clinicians and administrative staff to socialise in the reception area when there were no surgeries and I spent a lot of time here. However, at lunch time the majority of people congregated in the coffee room and I would also go in there to take part in the conversations and take notes. At these practices my presence seemed more notable than at Corryhabbie and staff constructed a particular presentation of their practice in their conversations with me. This reactivity should be born in mind when considering the data; however, this presentation in itself told me a lot about the ideals to which each general practice aspired. The reaction to my presence also seemed to lessen after the first few days and as I started going in and out of the practice conducting interviews, which mimicked the behaviour of many of the clinical staff and also perhaps provided a more recognisable pattern of work to those taking part.

At Corryhabbie the difficulties of recruitment and initial suspicion discussed above lessened following more thorough explanations, and whilst my note taking and questions in the reception area were initially questioned, my note taking at break times in the coffee room was not. In addition, my presence did not seem to influence the way the staff interacted with each other, possibly because the practice employed so many staff, and, as a training practice, they were used to having trainee doctors and nurses who would be about my age, coming in and out of the surgery. However, the staff at the

practice seemed unsure what role I was playing and how to incorporate me into the practice. For example, my frequent presence in the coffee room seemed to confuse the one GP who tried to encourage me to study in the practice's library like the medical and nursing students. These responses seem to suggest that the nature of my study was still not fully understood despite my repeated explanations. This practice was also very large and complicated and I felt that I was only just beginning to skim the surface of its complexity after the two week period. However, the focus on diabetes care meant that I was able to effectively look at one particular area of the complex whole.

As discussed above, I also collected documentation outlining the development of the diabetes clinic and any practice based protocols if they were available. This provided a background to my analysis of my interviews and informed my understanding of the development of the organisation of care over time. As discussed above, the MCN guidelines which professionals claimed to use in interview were also collected for analysis. This was done after the completion of fieldwork as only then was it clear from professionals' interviews which guidelines were relevant.

Process of data analysis

> There is no particular moment when data analysis begins. Analysis is a matter of giving meaning to first impressions as well as to final compilations. (Stake, 1995, 71)

Qualitative analysis can be understood as a process, a sifting through and winnowing down as concepts and themes emerge and develop through the period of data collection into a period of analysis and writing (Hammersley and Atkinson, 1995, 208). For each case study the data from interviews, observation and documents were stored and organised using NVivo 7, a piece of qualitative research analysis software (QSR International, 2006). This meant that the data from each case were easily retrievable. NVivo also enabled the data from the three cases to be coded alongside each other, facilitating subsequent cross case analysis.

The first step in analysis was to thoroughly familiarise myself with the data. This was facilitated by reading and re-reading all fieldnotes and interview transcripts in full, and writing summaries of interviews and descriptions of the practices and primary care diabetes service based on my fieldnotes. The analysis continued along a thematic approach and concepts and themes were developed inductively from the data with the research questions in mind (Boyatzis, 1998; Seale, 2005). This was an iterative process of developing concepts by repeatedly returning to the data and constantly revising these concepts to build an understanding of themes and hypotheses from the data. The analysis aimed to create an understanding rather than trying to prove or disprove a prior hypotheses (Hammersley and Atkinson, 1995; Patton, 2002; Yin, 2009). So, for example, whilst an early thematic analysis of my fieldnotes and documents yielded various possible concepts, or 'codes', these were initially generally descriptive. Hammersley and Atkinson observe (1995, 212) that this is often the case, but that through the ongoing process of analysing the interview data these codes were developed and modified until they eventually became part of the theme of 'understandings of holism' which will be presented in the next chapter.

With three case studies each containing two embedded units of analysis, a structured approach to managing the data analysis was essential. This was aided through the continued use of the original research questions and sub-questions outlined at the beginning of this chapter, as these provided a conceptual focus (Stake, 2006). I considered each of the research questions in relation to each of the cases, and developed themes from the data which were relevant to the research concerns, or which emerged as significant emic concerns. This approach worked well, partly because my research questions each related more to one "embedded unit of analysis" than the other. For example, an analysis of the influences shaping the organisation of care was largely informed by data from observations and interviews with professionals, with information being confirmed or furthered by my interviews with patients. For example, at Silvenea, patients told me they had been asked to vote on whether the practice should introduce an appointments system. In addressing my second research question, patients' interviews

informed the analysis to a larger extent than professional interviews or observations. After all only they could explain how they perceived and experienced their health care and their condition. However, analysis of data from each embedded unit was informed by the context of the case study as a whole, and understanding each case study as a whole was the next step in analysis. In this way, the 'story' tracing factors influencing the organisation of care, to patients' experiences and perceptions of diabetes, was outlined for each case. Finally, a cross case analysis compared the themes and relationships emerging in each case study with the next. The details of the process of analysis and its various stages are outlined below. At each stage of the process, a summary and initial analysis was written and discussed with my supervisors who were rigorous in questioning my interpretations and often sent me back to the data to think about alternate explanations.

The stages of analysis

- ***Stage 1*:**

Familiarisation through transcribing and checking other's transcripts, writing descriptions of the practices, and summarising interviews. The research questions and sub-questions were used to provide a series of conceptual foci for the analysis.

Stage 2:

What influences the organisation and provision of diabetes care in primary care?

At each case study in turn a thematic analysis of fieldnotes and professional interview transcripts was conducted. In analysing the interview data it was necessary to bear in mind that the content of the interview may be influenced by its context and the particular presentation of self that person wished to portray (Riessman, 1990). Hence, when analysing the data I tried to pay attention not only to the content of the interview but also, its context, the presentation of the self the interviewee was constructing through their stories and what remained unsaid.

Thematic codes were noted for each interview and then refined for each case study and stored in NVivo. As I moved from case to case I added to these codes and developed new ones, going back over case studies as new codes suggested themselves from the other cases.

I wrote an initial report for each case outlining factors apparently influencing the organisation of diabetes care in each case on the basis of this analysis. Comparisons were then made between the cases for each of the factors identified. As the analysis continued the themes identified from these embedded units in each case were kept in mind and were returned to in an iterative fashion if data from patients' interviews suggested alternate or new ways of interpreting each case.

Stage 3:

How do patients at each practice perceive and experience their diabetes?

Analysis was based on patient interviews and was conducted for each case study, one at a time. Codes for the patient interviews were developed for each case and then the data was reviewed and codes modified and added to in light of themes emerging from the other cases.

I wrote an initial report on key themes emerging from patients' accounts of their diabetes. It was noted that there were many similarities in patients' accounts across the three practices. This report reflected many of the observations found in previous research into patients' experiences of living with diabetes, but added some observations on how patients' perceived disease progression. These informed the analysis presented in chapter six.

Stage 4:

What are patients' perceptions and experiences of the diabetes services they receive in primary care? Do these relate to their perceptions of their condition and their role in managing that condition?

Analysis was based predominantly on patient interviews at each case study. Particular attention was paid to the way in which they presented their experiences and expectations of health services and the meanings they attributed to these experiences. Attention was also paid to their expectations for their own role in diabetes care.

This was written up as a report for each case study and discussed with my supervisors. This led me to note that there were differences in the meanings patients' attributed to the organisation of their care. The analysis of patients' interviews were enhanced by my detailed understanding of that care organisation which was also informed by my observations and professional interviews.

Similarly, the roles patients described themselves as playing and desiring in making decisions about their disease management differed. Explanations for these differences were looked for across the practices in the characteristics of the patient sample, for example ages and length of time since diagnosis. However, as will be discussed in chapter eight, differences were found to be more closely associated with professionals' accounts of their approach to patient "empowerment".

Stage 5:

Developing understandings through understanding each case study as a whole and subsequent cross-case analysis

In order to understand patients' interpretations of the services they received and their desire to be involved or not in treatment decisions, each case study needed to be considered as a whole and cross-case analysis conducted.

Hence, a possible understanding of the way in which patients attributed meaning to the organisation of their diabetes care emerged through drawing comparisons between the different case studies. For this it was necessary to have both an understanding of professionals' accounts of the organisation of diabetes care and the practice context, as well as patients' accounts of this in each case. Themes presented in chapters seven and eight became apparent only when cross-case comparisons were drawn.

Similarly, the differences I found in patients' desire to be involved in treatment decisions could be better understood within the context of each case study as a whole. Only by placing patients' accounts alongside those of professionals did possible explanations for the relationship emerge. Moreover, only when this relationship explained variation across and within all three cases was it considered a valid hypothesis.

Conclusion

In this chapter I have outlined the methodology for the research, the results of which will be presented in the next five chapters. Adopting the case study design of the research was an intensive and time-consuming approach and the pros and cons of this will be discussed further in the final chapter. However, the multiple case study design enabled a detailed understanding of the organisation and provision of diabetes care, and how health services may inform patients' perceptions of their condition, as will be evidenced in the data presented below. In the next chapter I will provide a description of each of the case studies by way of an introduction to these, whilst also identifying some possible reasons for differences in how they organised their diabetes care.

Chapter 4: Integrating type 2 diabetes care into the "generic and holistic" approach of general practice.

Introduction

In this chapter I will introduce the general practices which formed the hub of the case studies in this research and outline the organisation of diabetes services at each. I will focus particularly on the organisation and provision of the annual diabetes review appointment as, for many patients, this was the main or only diabetes care which they described receiving. I will then go on to highlight and reflect on the similarities and differences in the provision of diabetes care across the three cases. I will argue that, although there were many similarities, variations remained in the organisation of care which reflect differing interpretations of the meaning of 'holistic care'. These variations contrast health policy's assumption of a uniform and disease orientated approach to holism in primary care.

Health policy justifies moving chronic illness services into primary care on the basis that patients will benefit from a "generic and holistic approach". This is exemplified by the quote from the white paper "Partnership for Care" (2003) below:

> Primary Care is particularly well placed to meet these challenges [of chronic illnesses such as diabetes], as one of its strengths is the ability to provide a generic and holistic approach to care, which is so vital when a patient presents with more than one condition. (Scottish Executive, 2003, 36)

The policy assumes a uniformity of approach and definition of holistic care and a lack of variation in the way diabetes care might be integrated into primary care and general practice. Moreover, it implies that 'holism' means caring for "more than one condition". This understanding of 'holism' is also reflected by the new GMS contract QOF targets for 'holistic care', which reward practices for achieving targets in all disease areas, rather than following a biopsychosocial approach.

In contrast to the assumptions of health policy and the findings of previous research considering the impact of the nGMS contract (Checkland et al., 2008; Huby et al., 2008), I will show that differences in diabetes care organisation persist and are related to the differing practices' ethos, understandings of 'holistic' care and approaches to relational continuity. In the next chapter I will then go into more detail about why the diabetes care within each practice was organised as it was and go on to discuss how this related to the organisation of care with the various professionals based outwith the practice, such as DSNs.

Silvenea Island Surgery

Silvenea Island Surgery is a remote and rural dispensing practice situated on an island off the coast of Scotland. The practice provides medical care for c.1,000 people spread over a large rural area including several other islands. However, it is only 13 miles from the nearest town, Oldtown (population c. 8,000) (SCROL, 2001), with a Rural District General Hospital which provides emergency, general medical and general surgical services. Significantly for this study, the local rural hospital also acts as a base for the area's DSN. However, Silvenea Island is over 100 miles from the nearest city with a consultant-led diabetes clinic.

In 2000 the surgery moved out of the fulltime GP's home into a building next door. This was purpose built by the current fulltime GP, Dr James Harrison. From the outside the

building resembles a small bungalow and Dr. Harrison explained that this was so that the practice could be easily converted into a house if, on his retirement, no one was willing to take up the GP post on Silvenea.

At the time of my fieldwork, the practice had two GP partners, one full time and one who travelled over 130 miles to work at the practice two days a week. Also employed by the practice were two part-time receptionists (one of whom is practice manager), a part time health care assistant, and a practice nurse who worked four hours a week. The district nurse for Silvenea also worked from the practice and coordinated closely with the GPs. In addition, a peripatetic district nurse, who covered a large area encompassing several general practices, was based at the surgery a few days a week. With the exception of the part-time GP and peripatetic district nurse, all the staff who worked at the practice lived on Silvenea or its neighbouring islands and were active members of the community; for example, they sat on the community council. A physiotherapist, community psychiatrist and podiatrist also came out from their base at the district hospital to run clinics every few weeks at the practice.

Everyday care

The overall approach of the practice was informal and personal. In a two week period I only once saw the practice manager ask for someone's name when they appeared at the reception. This person was a visitor to the island. She welcomed everyone else by name as they came in and noted their first name in an open diary at the reception 'window'. There was no appointment system at Silvenea; people arrived, chatted to whoever was working on reception, sometimes for up to ten minutes, and then went into the separate waiting room to wait their turn to see the doctor. Some patients told me that sitting in the waiting room could be quite a social occasion, chatting to whoever was there. For each patient the doctor came out of their room, collected the next person's notes from reception and then went to greet and escort them to the consultation room.

Whilst transport around the island(s) could be difficult, GPs and district nurses spent much of their time carrying out home visits. In addition the GP had been involved in helping to establish a community run voluntary car service which acted as a pseudo-taxi service to help people reach the surgery. I also witnessed the health professionals going out of their way to give patients lifts home following appointments and several patients I interviewed told me that they had a lift home in the past from the professionals at the practice.

A personal and generalist understanding of holism

"Personal knowledge" of the patients underpinned the approach of the professionals at Silvenea and was very highly valued by them. Dr. Eilidh Crawford, the part-time GP, commented:

> I think that the personal level of care, the personal knowledge of patients, and the personal knowledge that patients have of their doctors is a tremendous asset; unquantifiable in the benefit that it brings to people.

Personal knowledge of patients worked in two directions. It was both the knowledge that a doctor had about their patient, but also the personal knowledge patients held about their doctors. This knowledge was based on social connections outwith everyday general practice; it meant knowing people within the context of the community as a whole. It also blurred the boundary between the identities of the clinicians and practice staff in their professional roles and in their private lives. For example Dr. James Harrison explained:

> Every time I go to the shop, you know, there is some [social] connection[7] and all of these connections then come back to what you were asking about [treating people with diabetes]. I need to build up what my personal construct

[7] Dr. Harrison had recently read Farmer's article *Connected care in a fragmented world: lessons from rural health care* (2007) which had appeared in the BJGP only a month before I started my field work. He felt that Farmer had articulated what was important in rural general practice very well, and his responses reflect the language she used in her article.

> of that person. What would be in their best overall interest? But, the only way I can really know that is by knowing [about the person's wider life].

Similarly, the health care assistant described how she saw her and the district nurse's roles as enhanced by their involvement in the community:

> Knowing as many people as we do in our practice, it just gives you a greater knowledge and an understanding of all your patients, even though they're maybe not coming to the surgery. Because it's a small community, you know them socially, and you're always aware [of their health and wellbeing].

According to these professionals knowledge gleaned from outwith the health care context was not only "a tremendous asset" (Dr. Crawford), but core to their way of working. It informed treatment decisions and supported the monitoring of patients' health. The "personal knowledge" or "connectedness" (Farmer, 2007) of the professionals' approach extended the notion of holistic care beyond the disease-centred model of health policy and even beyond Engel's (1977) biopsychosocial model. The reciprocal nature of the personal knowledge shared between patient and clinician informed the professional relationship in ways which reached beyond individual health care encounters. This knowledge also informed how and when these encounters occurred; for example, the professionals' social 'awareness' of patients meant that the consultation was not always initiated by the patient, and the knowledge drawn on within consultations may also be drawn from social interactions outwith previous medical consultations.

It has been observed elsewhere that this merging of social and professional roles also promotes a mutual sense of responsibility and interdependency between patient and clinician. On the basis of focus groups with patients in both urban and rural areas, Farmer et al. (2006) found that patients in rural areas tended to consult less often because of the social relationship they viewed themselves as having with their GPs.

However, Samantha, the peripatetic district nurse at Silvenea, highlighted some of the problems with the other professionals' use of social knowledge and willingness to go

over and above their defined professional roles. For example, she noted that by booking the voluntary car service to bring a patient to an appointment, this was disempowering for the patient. In general she observed that:

> There probably is a lot taken off folk and done for them and they're disempowered really, aren't they, when that happens. The control's taken away from them. It's almost like, well, I have to come to that appointment now, don't I, cos the car's gonna be booked for me.

Because the professionals were so active in their provision of care this left little room for the patient to maintain control over their own use of the health service.

The approach to holism of the professionals at this practice also emphasised generalism. The district nurses and GPs proudly told me about their extended roles during my time at the practice. For example, the district nurses would carry out many of the tasks which might commonly have been undertaken by the practice nurse and the GP described attending traffic accidents in a way which would not be typical in an urban environment. Dr Harrison suggested that generalism was core to rural general practice and a key reason why he did not have nurse-led clinics at the practice:

> The concept of generalism in a rural environment I think is very important… generalism is important and nurse led clinics usually end up led by specialist nurses and sometimes the population just isn't big enough. Specialised nurses may well work in a large practice but I'm not entirely convinced what the case is in a rural area.

Dr. Harrison is making an important point, namely, that a large population is needed to provide sufficient clinical experience to maintain the expertise of any specialist clinician. However, this quote also demonstrates another theme which ran through my interview with him and my conversations with the various professionals over my time at the practice. Silvenea very much identified itself against larger, urban practices. Indeed this was the reason they expressed for taking part in my research, that they felt that the approach of rural practices was under-represented and under-appreciated, leading to health policies which did not necessarily work well in a rural environment.

Continuity of care

The "personal knowledge" approach to holism at Silvenea was supported by an emphasis on the benefit of long term continuity of care, as is exemplified by the following quote from Dr. Harrison:

> Continuity of care is key to my form of general practice… I mean continuity in its biggest sense. I'm waiting for the first baby that I delivered to have [a baby]… I would see that as being a landmark in my personal care.

Continuity of care at Silvenea might extend over a large part of a person's life and across the generations of a family. Long term continuity and mutual personal knowledge in the patient-professional relationship were perceived by to further what Dr. Crawford termed, "a tremendous level of trust and acceptance from the patients".

However, Dr. Harrison presented his approach to general practice as a dying breed. The personal level of commitment needed to provide a form of general practice which blurred personal and professional identities is no longer a popular way to work, as has also been observed in Jones and Green's (2006) study of "shifting discourses of professionalism" amongst early-career GPs. Equally, the increasing specialisation within general practice was viewed by Dr. Harrison as a threat to the generalist model needed in rural settings.

Dr. Harrison told me that he worried he would be the last GP to be based on Silvenea Island and that in future the practice would probably become a branch surgery of a larger practice in Oldtown. To try and prevent this he felt he had a responsibility to leave the community with a viable business to tempt a doctor to take his place:

> Part of my role in the community I see as leaving a sustainable model and so when I retire, it will be job advert that will have, you know, 10 applicants because it's such a good job.

Hence, the approach to general practice was not only about "connectedness" and long term relational continuity, the practice was also a business which was presented as

having a moral responsibility to the community. One of the practices in Huby et al.'s (2008) multi-sited ethnography also presented themselves as "old fashioned" and "dying" style of general practice. However, Huby et al. (2008) noted that the practice in their study was now being driven very much by meeting the new approach of QOF targets. Like the practice in Huby et al.'s (2008) research, Silvenea had also achieved very highly in QOF and hence continued to be a successful, up to date business (96% of available points, above the Health Board's average of 93% (ISD Scotland, 2006)). Although, the full-time GP worried that his general practice would cease to exist in the future the practice was actually a successful business. Interestingly, the part-time GP also attributed this success of the practice in the QOF their 'personal' approach to general practice, an approach:

> I think we do very well [in the GMS contract] and I think that comes from, a level of trust that the patients come and open themselves to the service, open themselves to the doctor, permit, allow and trust that the routine care is that which is appropriate and recommended.

Dr. Crawford was suggesting that the high level of trust their patients had in their doctors at Silvenea meant that the practice as a whole was successful in the nGMS contract. Because patients trusted the doctors they were willing to attend appointments and agree to tests, all of which are necessary to meet the QOF targets. This includes the targets for diabetes care, and it is to how diabetes care was organised at Silvenea that I will now turn.

Organisation of diabetes care

The diabetes review at Silvenea differs from everyday care in that patients were asked by the practice to attend a specific appointment rather than initiating the health care encounter themselves and using the open access system. Anna, the practice manager, maintained a small box of note cards with the patients' names organised by the month they are due for their review. As the months come round, Anna sends each person a letter informing them of the date and time of their appointment. She told me that, if this

time did not suit the patient, they would phone and change it, and if the patient did not attend their appointment, she said she would "chase" them through phone calls and letters until she managed to arrange another appointment, or at least found out why they were not coming.

A week before the diabetes review appointment the district nurse told me that she would arrange to take blood samples from patients either at the practice or in their homes. This was so that the results would be back in time for the review appointment. Elsewhere one might expect this task to have been undertaken by an employee of the practice, a GP, nurse or phlebotomist, as happened at the other two case studies. It was partly a result of the good working relationship and flexibility of roles, which the professionals claimed were an inherent part of rural healthcare, that this task was undertaken by the district nurse.

The results of the necessary blood test were, I was told by Anna, then recorded in the computer-based patient records using the "Gpass" (General practice administration system for Scotland) system in order to meet the requirements of the contract. However, paper notes were still the main way of recording patient data to inform daily practice. Dr. Harrison explained that this was partly because he found the computer-based notes cumbersome, and because he was concerned about a loss of confidentiality if and when computer-based notes were shared with the hospital.

At Silvenea, diabetes care was separated from the everyday general practice in that it was organised by appointment, but was also part of the care provided by Dr. Harrison and as he saw it, was part of his general role:

> I would see my role and work as being all aspects of providing general medical care and part of that care is looking after diabetics.

Diabetes care was just one other aspect of general practice as a whole. It was simply part of the generalism of the rural practitioner, and, like other areas of practice, was informed by personal knowledge of the patient. Hence, whilst the appointment differed in its

organisation and in the recording of the data for the contract, the principles underlying the way diabetes care was provided were entirely congruent with those of the practice in general. This approach to general practice and the organisation of diabetes was not replicated at the other two case studies, as I will now go on to show.

Corryhabbie Health Centre

Based on the Scottish Executive's Urban/Rural classification (2005), the largest group of patients at Corryhabbie Health Centre live in an urban area. The main practice is based in the centre of a large commuter town of over 10,000 inhabitants, but also covers the surrounding farms and smaller settlements. The practice also has a branch surgery in the next town, and both practice locations are about 30 minutes by car, or 20 minutes by train, from the nearest city with a consultant-led diabetes clinic.

The main practice building is a flat-roofed, brick building constructed in the early 1970s when three local general practices amalgamated to make a larger health centre. However, the practice has outgrown this building, and they are struggling to find space to accommodate the multiple professionals based at the centre.

At the time of my fieldwork 16 GPs and over 40 other clinical and administrative staff were based at Corryhabbie, providing care for more than 16,000 patients. The majority of these clinicians did not live in the town. Some diabetes care also took place at the community hospital in Corryhabbie which provided a space for the local DSN and community dietician to run clinics and education sessions for patients newly diagnosed

with type 2 diabetes. Rates of diabetes at Corryhabbie were perceived by the health professionals to be increasing fast, which they attributed to the town growing in size and more cases being identified (their diabetes register grew by 80 patients in 2005-2006 (ISD Scotland, 2007)).

Everyday care: 'Innovative' team working with clear divisions of labour

Appointments in GPs' 'surgeries' were available to be booked 48 hours in advance. Half of the appointments were "released" at 8:30am and the other half at 1:30pm and at these times the phones in the reception area rang incessantly. At least three receptionists at a time were involved in making appointments and adding patients who wanted to be seen the same day to a triage list for the GP on duty to call back.

When patients arrived for their appointment they waited to be acknowledged at the "front reception", which was a high desk a metre wide and surrounded by a glass barrier with sliding windows which were closed when the receptionist did not want to be disturbed. This area adjoined the main reception by way of a door which was kept closed. The receptionists took it in turns to work on the front desk. However, the receptionist Sarah worked there more than most. I was told by the others that the desk was not a popular job because patients could be threatening and abusive, but Sarah was good at dealing with this because she was "tough" and the "patients were scared of her". The youngest receptionist, Julie, told me that it was a hard even to work on the phones in reception because patients would often get quite angry, for example, if they were unable to get an appointment.

At the front desk, patients would say their name and who they were there to see. However, this was rarely sufficient because the appointments system used dates of birth first, and names second, to identify the correct patient. Patients were, therefore, asked to identify themselves first by the numbers making up their date of birth. Once they were identified on the computer appointment system, patients were then directed to sit in the main waiting room or to go to one of the secondary waiting areas. From there they were

called to the nurse's or GP's consultation room by way of an electronic voice and LED screen. Finding the correct consulting room was not always easy as the practice was a complex of multiple corridors, and even at the end of two weeks I found I often took a wrong turn.

Corryhabbie Health Centre was big and busy, and the approach resembled that of a business offering a range of services, which reflected the specialisations and further training of the clinicians. Corryhabbie was also a teaching practice and as such had a focus on training nurses and junior doctors, who each came to the practice for six months at a time. The practice as a whole had a strong interest in teaching and had a history of researching their own care provision. I was told by the lead GP for diabetes that this was why they were willing to take part in my research. They saw themselves as innovative and up to date, and, also partly because of their size, considered themselves leaders in primary care in the area.

Working as a team also seemed to be core to the professionals' espoused values at Corryhabbie. Dr. Andrews commented that "people take a pride in being part of the health centre team." Several activities were organised by the GPs to consciously build the practice as a "team", such as an arts project and social events. However, despite this, the practice seemed to operate more along the lines of multiple teams formed around professional identities and following apparently quite rigid divisions of labour. During the time I was at the practice I observed very little informal communication between these professional groups. Only if professionals had particular concerns about a patient did they cross the room to have a discussion with a professional from another group. The conversations of this nature which I witnessed were short and the various staff then returned to their usual professional groups to socialise. In the staff room GPs would sit in one area whilst administrative and nursing staff would sit in another. There was more socialising amongst the nurses and administrative staff, but the separate teams (for example, district nurses, administrators, receptionists or treatment room nurses) would often go for coffee breaks at different times and would not necessarily interact with one

another. I was told in interviews that this segregation was normal at Corryhabbie. Interviewees presented this segregation as a product of a conscious division of labour through the creation of separate teams which had taken place about ten years earlier. However, it was also described by one the nurse as a remnant of an old "class system", reinforcing traditional boundaries between the medical and nursing professionals in particular. Despite this, there were various ways in which communication across these professional teams and the delegation of responsibility for patients requiring greater personal support was facilitated in the practice. These included some informal discussions of patients in the staff room, as well as formally organised meetings between particular clinicians, and extensive use of computer based notes system. All patient notes were electronic and the paper notes which filled every corner and cupboard of the reception area were used only for audits. In addition, two wipe boards were used to facilitate communication between staff by notifying them of information about particularly vulnerable patients, such as the terminally ill, and informing staff when patients had been hospitalised or died.

In addition to the organisation of the various clinical and administrative teams described above, the management structure of the practice had also followed the guidance of a "business guru" to create a division of labour for the business aspects of the practice. The result of this consultation was that each GP undertook a specific role in the management of the practice as a business, like a board of directors. Dr John Shore explained that there "needs to be lines of responsibility and accountability and some degree of clarity as to who's doing what". Dr Shore described his role as chairing business meetings, another doctor was "administrative director" and Dr Andrews described herself as "director of education" at the practice. This business like division of labour was more pronounced in this practice than in the other two case studies, most probably because of its size.

Interestingly, this emphasis on clear divisions of labour and teamwork also translated across to expectations of the ideal patient-professional relationship (with particular reference to chronic disease management):

> It's basically the patient in charge of their own lifestyle, the patient doing 50% of the work and us doing 50%. (Pat, chronic disease nurse)

As in the quotes above, the patient was presented as a rational partner with a clear designation of who was responsible for doing what in that partnership. In this relationship Vicki, the lead nurse for diabetes, expected that her patients would "soon walk away if they don't feel they're getting the care they deserve or want". She assumed that, like a model consumer, patients have the individual freedom and self determination to 'exit' if unsatisfied with the goods they are receiving. However, this is misleading as Corryhabbie was the only practice in town, so 'exit' would have been difficult for patients. Hence, Corryhabbie represented a particular approach to general practice, which included assumptions about the role of the patient. As I will now go on to outline, the professionals at the practice also adopted particular understandings of holism and continuity of care which fitted into their general approach.

Multi-morbidity holism and condition centred continuity

Understandings of 'holistic care' at this practice were shaped in opposition to the perceived approach of secondary care and focused on an awareness of the multiple conditions a patient might have. For example, Vicki, the practice diabetes nurse, compared her approach to that of the DSN's who she said had a "mindset focused on secondary care". She also used the example of a DSN she knew who was absolutely brilliant with the patients' diabetes but neglected their cholesterol, to highlight that her approach was more 'holistic' because it involved a consideration of all of the diseases from which a patient may suffer. Similarly, Dr Christina Andrews, the lead GP for diabetes at this practice, explained in her interview that diabetes care was better dealt with in primary care rather than secondary care because: "diabetes has to be integrated with all the other bits and pieces – illnesses and personality issues and all the rest of it".

The understanding of 'holistic' care at Corryhabbie focused on integrating a consideration of illnesses both physical and psychological, but did not always appear to emphasise knowledge of the patient's social situation. It was a form of what I term "multi-morbidity holism".

Personal knowledge of the patient was simply not seen as a priority in everyday general practice as it had been at Silvenea and opportunities to gain such knowledge were also limited because relational continuity of care was difficult to maintain in everyday practice. Dr. John Shore explained:

> The approach that we take in the practice is that we give patients the choice of who they go to see… but we try to encourage continuity of care, particularly within one episode, so if someone comes to me with dyspepsia… we try to say, keep coming to me at least for this episode… The reality is that the size of the practice, the numbers coming and going, it is actually very often quite difficult for patients to make a new appointment with the person that they saw before, it's quite a problem… continuity is a bit of a problem, but it's not critical… with emergency and acute stuff… it doesn't matter too much who you see as long as it's somebody who knows what they're doing, a sort of review of a chronic condition is not quite the same scenario, but we see it as being desirable if we can keep continuity… but I think in reality we won't achieve it that well.

Continuity in this excerpt is presented first and foremost as continuity over the period of one episode of acute illness, rather between a patient and one health professional no matter what illness is being presented. However, this illness continuity was still difficult to achieve. Whilst recognised as a desirable aspect of general practice, particularly in care for chronic illnesses, continuity of care did not emerge as a priority in the approach to everyday general practice. Indeed, patient choice appears as a higher priority in the quote from Dr Shore above. This is congruent with the role I have already argued professionals at Corryhabbie expected of patients. Namely, that they would be active agents in choosing the healthcare services they wanted from the clinician they wanted.

Since, relational continuity between a patient and professional was not often achieved this meant that the consideration of a patients' various illness could only be achieved

through communication between the health professionals involved. 'Holistic' care was constructed through the communication of the professionals each providing care for a different illness presented by a patient. Dr. Christina Andrews described one particular case where this system had failed whilst I was at the practice:

> Because there are so many patients its very difficult; although we try and maintain continuity… there still isn't always quite the awareness of absolutely everything that's going on… That was what was happening at coffee time. We [the doctors] were talking about a guy who's got some rare tumour who'd come out from the city hospital to stay with his mother and father, and his father's got lung cancer. And there'd been a phone call from secondary care yesterday saying could you give them more support…but it is a horribly complicated situation and several of us knew about it but nobody has sort of got long-term responsibility for it.

In Dr. Andrews' description, the system of continuity for each individual condition has failed the patient by not taking into account the context of his family. No one had been fully aware of, or taken responsibility for, the whole situation. The system of 'holism' through inter-professional communication had failed until a crisis point had been reached. Only then was there further communication about the reallocation of the division of labour and who should take responsibility for the situation as a whole. In the following section I will go on to outline the particular approach to diabetes care at Corryhabbie and consider whether this reflected what I have termed above 'multiple-morbidity' holism and 'illness continuity' of their everyday general practice.

Organisation of diabetes care

As I mentioned above, many of the GPs and nurses at Corryhabbie have specialised in particular clinical areas. The diabetes clinic at the practice takes place two days a week and is carried out by Vicki. Vicki completed the Bradford diabetes diploma in the late 1990s and is employed as a peripatetic nurse specialist running diabetes clinics at several practices in the area. Dr. Christina Andrews, who also has had further training through the local consultant-led clinic and experience of providing paediatric diabetes care, fulfils the role of the GP lead for diabetes. This involves discussing any problematic

cases with Vicki on a Thursday afternoon but does not involve consulting with the patients. At Corryhabbie Vicki sees all patients who have been diagnosed with type 2 diabetes since she started the clinic in 2000, and all type 2 diabetes patients over 70 years old. All other patients remain either in hospital-only care or are receiving shared care with the consultant led clinic and Vicki. Vicki also refers patients to the local community dietician and podiatrists, as will be discussed in greater detail in the next chapter.

Diabetes review appointments were arranged by Susanna, who was employed specifically to do the administration for the diabetes clinic and the minor surgery clinic at the practice. The recall system is based on a list of patients requiring review, which the assistant practice manager prints for Susanna combined with Vicki's notes to Susanna to recall patients earlier if need be. Appointments are planned using the computer system. Susanna sends out letters with two appointments for each diabetes review, one for the patient to have their blood taken by the phlebotomist and then an appointment with Vicki the following week. Patients could call Susanna on a direct number to cancel and rearrange appointments if necessary. The use of a direct number is to try and avoid patients falling into what Susanna described as the "pit" in the computer recall system and being forgotten, and meant that the diabetes service by-passed reception. Susanna also explained that if a patient did not attend ("DNAed") their appointment three times they were exception reported from the practice's QOF rewards, and would not be reinvited until the following year. No further efforts were made to investigate why a patient had not attended other than looking at the information boards in reception to see if they had been hospitalised or had died.

Once a patient's blood test results were returned to the surgery these were then entered into the patient records using "Docman" (PCTI Solutions, 2009), a system of scanning results and letters into the patients' electronic notes held on the "vision" computer system (INPS, 2010). This data entry was completed through the joint efforts of the

reception and data entry teams. In this way the blood test results were accessible to Vicki through the patient's electronic notes.

The organisation of the diabetes clinic generally reflected the well defined divisions of labour across the practice. It also engendered the principle of providing relational continuity for a chronic illness and sidestepped the problems of rearranging appointments through the main reception through its own administrative system. The diabetes clinic acts almost as a completely separate clinic linked to general care only through the discussion of 'difficult' cases between Vicki and Dr. Andrews and through the sharing of electronic notes and intra-practice referrals. Hence, the approach to organising the clinic at Corryhabbie reflected the overall approach to holism evident at the practice, namely that of creating a combined consideration of a patient's medical problems through inter-professional communication.

Strathfinella Medical Practice

Strathfinella Medical Practice is based in a village of c. 900 people but provides care for a large rural area and has a branch surgery in the small town 5 miles away. The practice's total list size is about 3,000. The adjacent small town also has another general practice with over 10,000 patients, and a community hospital. It takes 30 minutes by car or 50 minutes by bus to reach the nearest city and consultant led diabetes clinic at

Braeburn Hospital. Until quite recently the practice was based in a converted house but had moved to a purpose built building on the edge of the village centre in 2003.

At the time of my research, there were two full-time GP partners at Strathfinella, who took the lead on clinical decisions, and a practice manager, who focused more on administration and auditing, there was also a practice accountant. In addition the practice employed five reception/ administrative staff, two practice nurses, a health care assistant and two part time salaried GPs. The local district nurses were based at the other larger general practice in the town and passed through the surgery about once a week to collect their mail, but did not spend a substantial amount of time working or socialising at the practice. The local DSN, podiatrist and dietician, to whom the GPs and practice nurse referred diabetes patients, were all based at the consultant-led clinic in the city.

Everyday care

During the period of my observation, the practice was busy, but not overwhelmingly so. The overall impression I got was of friendly industriousness. Patients called the surgery throughout the day to arrange appointments and were often recognised by the receptionist over the phone and vice versa. Hence, a more informal greeting and chat would often follow the surgery's official phone response. Appointments could be made in advance but some appointments were always kept free to make them available on the day. The receptionists booked the appointment on the Gpass computer system whilst on the phone to the patient. Any requests for home visits were passed on to the duty doctor to telephone back and triage.

When patients arrived at the front desk some were known to the receptionists, who would greet them over the high wooden desk and, without needing to ask for their names, would mark that they had arrived on the computer system. Patients were then asked to wait in the large waiting room and would sit reading a book or chatting to other people, sometimes returning to the reception desk to chat with the staff. On a few occasions, people also returned to the desk to complain about having to wait ten minutes

or more for their appointment when surgeries were running late. When the time for a person's appointment came, the health professional they were waiting for came through to the waiting room, greet the patient and escort them to their consulting room.

Holism, merging the biomedical and the psychosocial

In our interview Dr MacLeod summarised the changes he had experienced since the introduction of the nGMS contract and the approach of Strathfinella practice as a whole:

> Some of the old fashioned general practice has gone because we're now basically trying to hit targets. Which is good, for target patients.
> **HM: What would you define as old fashioned general practice?**
> Being able to sit and have a natter and then thinking, oh I'll go and do a visit on so and so today… [now] you're constantly beating the clock and you don't have the luxury of spending time with patients

According to Dr. Macleod, the focus of general practice had moved from the social interaction of the medical consultation and the health care relationship, towards a greater emphasis on meeting and recording biomedical targets. He went on to talk generally about the nature of general practice and how he perceived his role within the community:

> General practice is kind of an old fashioned term now, isn't it?... I think general practice is being *the* doctor whereas primary care is all the clinicians contributing to the community based care…. GP strikes me as the old way. This person was a figurehead of the community, who was put on too high a pedestal, I think of the old GP of this village… and I wouldn't want to be there. I wouldn't want to be different. I want to go to Tescos such that I can just be a punter.

Dr MacLeod suggested that "old fashioned general practice" was characterised by the position of the GP in the community. This position involved merging personal and professional identities so that one was never just "a punter" but always "*the* doctor". The clinicians at Strathfinella aimed to maintain the separation of personal and professional identities and adopt a 'primary care' approach, in which they would be one of various community clinicians rather than "*the* doctor". They also aimed to provide evidence

based, up to date care, whilst maintaining a personal approach to the clinical consultation. Dr MacLeod again summarised this approach:

> If [guidelines] say do it that way, I'll do it that way. Therefore I think I'm then providing good care for my patients. But how one does it as an individual is the thing, if they walk out the door happy or not. That interaction still is important.

The integration of these aspects of care within the consultation lay at the heart of the approach to holism adopted at this practice, as was made particularly explicit in my interview with Dr. Scott when I asked her to explain what she meant by "holistic care":

> What do I mean by holistic care? Well, obviously, it's just a current jargon word that's good to use, isn't it; which is why I did it. My understanding is that in any disease area or any patient's problem… I provide [medical care] to the best of my ability hopefully keeping abreast of what is best practice… but I give the patient the opportunity to understand and have the opportunity to take up the best possible medical care, be that drugs or otherwise. I take on board the patient's perspective and concerns in delivery of that care and guidance about their condition, so, that if they have concerns, I hear them and I tailor my management to take their concerns into consideration.

Whilst Dr. Scott views 'holistic care' as "jargon", she also seems to have a particular understanding of what is meant by this. Dr. Scott situates "holism" within the context of individual consultations and, for her, it involves aspects of providing "patient-centred care" (Mead and Bower, 2000), which were not prevalent in the model of "holism" witnessed at Silvenea. In this model of what I shall term 'consultation-based holism' Dr. Scott incorporates involving, or taking into account, patients' own concerns regarding the medical care, into the biopsychosocial approach. Dr MacLeod's definition of holism similarly focused on his expectations of a good consultation:

> Holistic care is managing somebody as a whole. To me, if you ask what it is in practice, it means you can sit in with them for a whole hour and you can talk about everything about their illness and you manage their whole illness.

Providing holistic care at Strathfinella seemed to be closely related to ideas of what constituted good communication between professional and patient within a consultation.

As I will outline further in the next section, Dr Scott was concerned that the current organisation of diabetes care would mean that she would no longer "know" the patients well enough to inform decisions about their medication. In addition, in the diabetes drug review meeting with the practice nurse, Erica, I witnessed many occasions when both Dr Scott and Erica drew on their knowledge of patients' wider social circumstances gleaned from repeated consultations with that patient. Relational continuity with the patients was important in informing the clinical decisions made within this review, and was widely valued in general at the practice. For example, Erica, the practice nurse, commented that "a continued relationship with somebody is hugely important".

Patients were able to maintain continuity with a single doctor at Strathfinella. However, maintaining the opportunity for continuity had come into conflict with the organisation of an efficient appointment system, as was exemplified by concerns over Dr MacLeod's approach to relational continuity, which he explained:

> I tend to encourage continuity of care with one doctor and I'm criticised for that by my colleagues because I like to have my own patients and see them through their illnesses... And I think the patients will find a doctor they want to work with.

However, this approach was causing difficulties in the organisation of everyday care. Whilst I was at the practice, one of the complaints from the reception staff at the weekly team meeting was that the appointments were filling very quickly for Dr MacLeod and Dr Scott, and only slowly for the newer salaried doctors, making it difficult to organise appointments with the patients' preferred professional. They complained that this situation was not helped by Dr MacLeod refusing to encourage patients to see a different doctor and leaving the reception staff with the difficult task of trying to explain when patients could not see him because all of his appointments had filled. Continuity of care and ease of access were difficult to balance.

Professionals' approach to general practice at Strathfinella was underpinned by an effort to move from what Dr MacLeod termed an "old fashioned" model of general practice to

a modern "primary care" whilst emphasising patient-centred care in the medical consultation. The professionals at the practice are very consciously trying to balance managing the health of clinical cohorts of patients and meeting QOF targets, with the "psychosocial" care of individuals. The difficulty of how best to address these two sides of general practice were often highlighted as a problems over coffees and in my interviews with the GPs and practice nurse. Trying to achieve this balance was also about progressing as a successful business. The "old fashioned" model of general practice which focused on individual patient-professional interactions needed to some extent, give way to managing patients as cohorts in order to achieve in the contract, as Dr. Scott put it:

> We have to make money… and [so] we have to take into consideration what we need to do for the contract. We signed the contract and actually you can't ignore that.

Organisation of diabetes care.

Diabetes care at the practice was split between Erica, the practice nurse, Dr Scott and Dr Gion, one of the salaried GPs. Dr Scott took over the role of diabetes lead a few years earlier because she was interested in managing a "cohort of patients" and there was a need for someone to take on the role when the previous GP (Dr Sinclair) retired. Dr Scott told me that she probably read more about diabetes than other doctors at the practice, discussed cases more with consultants and attended more meetings and conferences which related to the management of a cohort of diabetic patients. However, she felt that any further formal training would be unnecessary as they viewed themselves as a relatively small practice with a relatively small number of diabetic patients. Dr Gion also had not undergone any further training but had offered to help because of the increasing numbers of patients with diabetes. He said he was confident that Erica knew more about diabetes than him and relied on combining her knowledge of diabetes, and assessment of the patient and their social circumstances with his more generalist knowledge. Erica was the only one who had received formal specialist training in

diabetes care, provided by the secondary care team for diabetes at Braeburn Hospital in conjunction with a local university.

The GPs were not routinely involved in patients' diabetes review appointments. Erica carried out the diabetes review appointment, which could be arranged for any time rather than being temporally separated into a specific 'clinic'. Then in a meeting between Erica and each lead GP, the GPs advised and prescribed medications and Erica brought her assessment of the patients' psychological and social state for consideration. In my observations of Erica's meeting with Dr. Scott this was furthered by the knowledge of them which Dr Scott had gleaned from when she ran the diabetes clinic alone two years earlier, before Erica was employed. Interestingly, it was this meeting between Erica and the GP which was referred to as the "diabetes clinic" by the administrative staff, perhaps because, unlike patients' appointments with Erica, it was temporally separated out from everyday general practice.

One of the receptionists, Annemarie, had the responsibility for organising patients' diabetes review appointments with Erica. She used a system of name cards filed by month in a small black box to keep a track of which patients should be seen each month. She also used her personal knowledge of the patients which she had built up through experience of organising their appointments to select a suitable time for their appointment. For example, she knew that Mrs Smith needed her daughter to give her a lift to the surgery and so she would arrange an appointment time when her daughter would be available to do that. Annemarie invited patients to their appointment by letter or by phone. If a patient wanted to make changes to the arranged appointment they would phone the surgery and were passed on to Annemarie. Annemarie told me that if a patient did not attend their appointment she would get in touch with them and arrange another at a better time. She told me that Strathfinella did not have many diabetes patients who did not come and they had only ever exception reported one person for this.

Following the nurse and GPs meeting to discuss clinical care, each patient was then sent a letter with their HbA_{1c}, blood pressure and cholesterol levels, and a comment as to what the next course of action might be, such as being seen again in three months. Patients commented that they were also particularly encouraged by the comments that the nurse wrote next to their blood test results in this letter. For example she wrote might write "well done" or "excellent" when a patient had reached a clinical target value. These target values were also outlined on the back of the letter. However, if any major changes to treatment were planned (such as change in the dose of a medication) the nurse or doctor would call the patient and discuss these proposed changes. A consultation with the nurse would be arranged for other more drastic changes, such as initiation of a new drug.

As in the generic care at Strathfinella, the organisation of diabetes care reflected the tension expressed by the health professionals between providing evidence based care whilst also continuing to enable 'personal care' within the consultation. This tension was much more explicitly discussed than at the other two practices. For example, Dr. Scott reflected:

> Since we started doing [the review clinic this way] diabetic control is much better because the medical model of management is not weakened by the patient-practitioner interaction. But we will see if patients are frustrated by the apparent loss of control… As a cohort I'm looking after them better. But whether it works as well at an individual level I don't know. Also it allows Erica not to be the one bearing bad news so she can stay as the supportive one and in a way side step this responsibility. So I allow Erica to use me in the bad cop role as it were.

At Strathfinella Dr Scott addressed the biomedical whilst Erica addressed the psychosocial, and the 'holistic' care was achieved by bringing these two together in the nurse-doctor meeting. However, they were aware that this excluded the patient from clinical decisions, an approach which directly contrasts with Dr Scott's presentation of holistic care above. Moreover, as Dr Scott no longer consulted with patients, she was

concerned that she might not take in the "patient's view into consideration enough" but she weighed this up against the need to provide evidence based care:

> You could look and say, well actually, if I distance myself from being influenced by that [the patient's view or preference], I will only be driven by the targets and I don't just mean for contract purposes but, actually if we know lower BP, lower cholesterol… actually in just outcome measures of blood results and therefore reduced heart attacks, strokes and so on … actually I'm going to do better.

In theory, with the reorganisation of the diabetes care, Erica 'knows' the patient and Dr Scott focuses on the biomedical assessment of their condition. Bringing these two sides together to try and provide biopsychosocial, 'holistic' care in the absence of the patient is, however, difficult. Ultimately this approach appears to favour biomedical targets over the psychosocial.

At Strathfinella there was a clear tension in professionals' accounts of trying to meet QOF targets for care whilst maintaining both a holistic and personal approach facilitated by relational continuity. This was also related to their conscious efforts to try and move away from "old fashioned" (Dr MacLeod) general practice and adopt a population orientated and evidenced based primary care. The approach to organising diabetes care in this practice reflects an attempt to overcome this tension, but distances the patient from clinical decisions. Hence, the organisation of diabetes care at Strathfinella reflects the understanding of holistic care as involving a tension in face of providing evidence based care and personal care which pervaded the approach to care in general at Strathfinella. However, the absence of the patient from clinical decisions was incongruent with the "patient-centred" care which the GPs claimed was also part of their holistic approach.

Comparisons

As the descriptions above illustrate, the three general practices differed in multiple ways ranging from their appointment systems to their understandings and provision of holistic

care and relational continuity. The professionals at Silvenea emphasised the provision of care based on personal knowledge of the patient. The approach adopted at Corryhabbie was to present the practice as a range of services provided in one location from which patients could choose. The approach to everyday care adopted at Strathfinella seemed to sit somewhere between the personal nature of care offered at Silvenea, and the businesslike partnership approach of Corryhabbie. Alongside these approaches the GPs adopted differing roles within the community. At Silvenea I proposed that the role of the GP, and indeed of most of the clinicians based there, blurred the boundaries between personal and professional. This was further emphasised by the fact that patients told me that the retired doctor or district nurse who lived on one of the islands was often still the first person they contacted if the weather was too bad to reach the main island or for small pieces of advice out of hours. At Strathfinella the GPs were striving to move away from this social position as 'the doctor', but still retained some social contact with their patients; for example, they recounted meeting and greeting patients in the street. Professionals at Corryhabbie seemed to adopt a role which maintained much more distance between their professional and private identities. For example, they did not tend to live in the village, and one GP who did, described how she had been concerned that patients might knock on her door and ask for advice.

The differing approaches or ethos of these three practices can be partly ascribed to their location and characteristics of the community of which they were part. Yet, whatever the full reasons for their differing approaches, professionals at each practice also presented different, local, understandings of holism and continuity of care. Moreover, these understandings appeared to reflect or inform the way in which diabetes care was incorporated into "generic and holistic general practice".

Varying conceptualisations of holism and continuity of care

At Silvenea holism was taken to mean combining a consideration of biomedical problems with shared mutual personal knowledge of the patient developed through social interaction both within and outwith a healthcare context. I have suggested that this

reflects rural patients' description of a relationship of "connectedness" described in previous research (Farmer, 2007; 2006). The corollary of this was the provision of long term relational continuity, which was understood as providing care for a person over the course of their lives and even across generations. This approach to holism, long term continuity and the generalism associated with a few professionals dealing with a wide range of illnesses, was presented as a defining characteristic of Silvenea as a rural general practice, in contrast to larger, urban practices. At this practice, diabetes care was viewed as part of general practice care as a whole and, although the organisation of review appointments was separated from the usual open access approach of the practice, diabetes care was provided by the GP who provided most other aspects of care. Hence, the organisation of diabetes care reflected the professionals' ideals of holism and continuity of care.

At Corryhabbie, the definition of holism was developed in opposition to secondary care services. Whilst secondary care was expected to only focus on one disease at a time, primary care considered each of the patient's morbidities in relation to others they may have. I have dubbed this approach 'multi-morbidity holism' and it was generally achieved through the communication between the differing professionals involved in the care of each of a patient's morbidities. Professionals aimed to provide continuity of care over the period of each illness episode; however, long term relational continuity was not considered necessary except in chronic illness. Hence, all diabetes care was provided by one specialist nurse, enabling goals of relational continuity for chronic illness to be met. This nurse also met with a GP once a week and made use of the computer-based notes in order to incorporate a consideration of the patients' other morbidities into her care, and reflecting the form of 'mutli-morbidity' holism espoused at the practice as a whole.

Finally, I have suggested that the professionals at Strathfinella presented the identity of the practice as moving away from, but continuing to draw on, aspects of an "old fashioned general practice" (Dr MacLeod). They were aiming to move away from approaches of "connectedness", which had until recently been dominant at their practice,

whilst trying to retain the provision of personal care. To the clinicians at Strathfinella, holistic care meant that they aimed to incorporate a consideration of the patients' socially situated concerns into the care they provided. Holistic care incorporated both the biological and the psychosocial, but interactions with, and knowledge of, the patient did not necessarily extend beyond the consultation. Staff at the practice continued to draw on social knowledge of patients from experience of organising appointments to arrange appropriate appointment times. However, this was not presented as a central aspect of the way they provided care in the manner that personal knowledge was used at Silvenea. Relational continuity in everyday general practice was viewed as important and facilitated through an appointment system where patients could choose which GP they wished to consult with. Continuity of care was also provided for diabetes care. However, as not all of the clinicians had equivalent knowledge of the condition, patients were not able to choose who they consulted with for their diabetes. In addition, the organisation of the diabetes clinic at Strathfinella divided the provision of holistic care. In a consultation with the nurse psychosocial concerns were addressed, whilst in a separate review of blood results and medication the lead GP and nurse discussed biomedical concerns and tried to incorporate these in their discussion with the psychosocial. This seemed to reflect a tension between the twin demands of meeting biomedical targets and taking into account the patients' social situation. However, this organisation also contrasted the emphasis on providing patient-centred care, which was frequently referred to as a concern at Strathfinella.

Similarities

In the accounts of the organisation of diabetes care above there are also striking similarities across the practices. All three achieved highly in the QOF targets for diabetes care: Corryhabbie gained 99.5% of all points available for diabetes in 2006-

2007, Silvenea and Strathfinella achieved 100%[8] (ISD Scotland, 2007). Reaching this level of achievement in the QOF for diabetes means that each practice was meeting the biomedically focused, financially incentivised, targets of monitoring and managing the health of their diabetes patient populations. Whilst Dr Harrison at Silvenea also tried to emphasise the vocational nature of general practice, all three practices were ultimately striving to be successful businesses and recognised themselves as such.

All three practices arranged some form of register and recall system for their patients with diabetes and organised a separate diabetes review clinic or special appointment in order to attain the biomedical targets of QOF and recorded the data from these consultations on a computer-based records system. However, many aspects of these organisations of diabetes care predate the nGMS contract, as all three practices had gone through the RCGP accreditation scheme on which much of the nGMS contract was based, and hence had organised their diabetes care at that point (RCGP, 2003). Also, the history and location of two of the three practices (Silvenea and Strathfinella) meant that diabetes care had been provided in those practices for approximately twenty years, perhaps explaining the correlations between the approach of the practice as a whole and their approach to organising diabetes services. The extent to which local approaches continue alongside or despite standardised processes and targets seems apparent in the *way* in which these are achieved as part of the broader ethos or approach to general practice.

Summary and conclusions

Similarities in care provision might be partially explained in terms of the practices' response to RCGP accreditation, reinforced through the financial incentives of QOF, and

[8] The practices involved in this study were not unusual in their high QOF achievement, the Scottish mean of the percentage of points achieved in QOF diabetes targets is 98.4%. (ISD Scotland, 2007).

partially attributed to a common biomedical understanding of diabetes and its management. However, differences in the organisation of care continued. These broadly reflect Armstrong's (1985) three models of the general practice ranging from 'old general practice' to the modern 'health centre' as outlined in the introduction. However, Silvenea is not a "vestige of an older regime of general practice" (Armstrong, 1985: 662), as all three are thoroughly modern practices, all performing to a similar level in current biomedically orientated measures of care provision. Rather than reflecting different stages of development in general practice, the three practices reflect different emphases on aspects of the defining features of general practice. They each presented a different organisational ethos and associated conceptualisation of holism and continuity of care.

In an ethnographic study of the introduction of the nGMS contract in four general practices, Huby et al. (2008) drew on Weick's (1995) theory of "organisational sensemaking" to argue that each practice presented itself in a manner which emphasised differing defining characteristics of general practice. However, they argued that these presentations did not reflect the organisational divisions of labour within the practices, which were becoming increasingly standardised in response to the nGMS contract (Huby et al., 2008). Similarly, based on the same ethnographies, Checkland et al. (2008) argued that, whilst all four practices continued to espouse the ideal of holistic care, they were adopting increasingly biomedically and disease orientated organisations of care; for example, by organising the care for different diseases into separate clinics within the practices. Checkland et al. (2008) suggest that the "definitional slipperiness provided space within which clinicians could continue to claim holism whilst engaging in working practices based on a quite different philosophy" (2008, 13). Professionals were following a biomedical orientation to care with whatever interpretation of holism they adopted having little effect on actual practice (Checkland et al., 2008).

In contrast to Huby et al. (2008), I have illustrated that aspects of the organisation of diabetes care were standardised across the practices and I have also shown that variation

in organisation persists. Moreover, I have argued this continued variation, particularly the extent to which diabetes care was integrated into "generic" general practice, was related to the understandings of "holism" and "continuity of care" espoused at that practice. Hence, unlike Checkland et al. (2008), I found that particular understandings of holism in general practice did seem to shape the organisation of diabetes care. The significance of this for patients' experiences of care will be discussed in chapter six but in the next chapter, I will continue my consideration of the various factors which shaped the organisation of diabetes care in each case study.

A central theme which will be developed in all of the following chapters, both in further discussing professionals' organisations of care and patients' experiences of that care, is the role of 'trust'. Hence, before moving on to present more of my analysis I will take a step to one-side to explain of the theories of 'trust' which I will draw on in my subsequent analysis.

Preface to empirical chapters five to eight: A conceptual framework of trust

Introduction

In chapter four I introduced the three general practices in each case study of this research and suggested that the particular understandings of 'holism' and 'continuity of care' espoused in these were related to the organisation of the diabetes clinic in each. In chapter five I will go on to reflect in greater depth on the details of diabetes care organisation in each case study. I will discuss how relationships across traditional professional boundaries, and the meanings associated with health policy instruments, influenced the divisions of labour in diabetes care. Subsequent chapters will then go on to discuss patients' experiences and interpretations of their care provision.

A central theme of the analysis presented in chapters five, six, seven and eight is 'trust'. As is clear from my literature review, trust was not a central concern of this research from its outset. However, differing varieties of trust emerged as a unifying theme across both my analysis of professionals' organisation of health care and patients' experiences of that care. I will argue that trust in inter-professional relationships shapes divisions of labour in the organisation of diabetes care, and patients' trust in their health professionals influences the meanings they attribute to their experiences of care. Hence, this short preface has been included in order to outline two theories which I have found useful in understanding the differing varieties of trust I recognised in my analysis.

Theories of trust

Definitions of trust vary but most share a basic understanding that trust involves an acceptance of risk or vulnerability based on favourable expectations of the actions of another person or persons (Hall et al., 2001; Möllering., 2001, 2006; Rousseau et al., 1998; Sztompka, 1999; Giddens, 1990; Luhmann, 1979). The specific theories which inform my conceptualisation of trust in this thesis are drawn from Möllering (2006) and

Sztompka (1999). I will use these two theorists' work alongside each other because they focus on different aspects of the concept as a whole. Möllering (2006) discusses how trust may vary in terms of its bases (the reasons for trusting), whilst Sztompka (1999) considers the expectations that trust entails (who we trust, and to do what). Möllering's (2006) theory, which is based on an extensive literature review, also integrates the approaches of many thinkers from different disciplinary and theoretical backgrounds. It therefore provides a broad and flexible understanding of the possible bases of trust. Hence, drawing on both Möllering's (2006) and Sztompka's (1999) theories provides a particularly useful way of conceptualising the multifaceted nature of trust, which builds on previous thinking.

Möllering

According to Möllering (2001), trust involves three elements: interpretation, suspension and expectation. Interpretations of everyday experiences of 'reality' constitute the "good reasons" for trust; they are the basis of trust. A state of expectation is the final outcome, the state of trusting itself whilst, suspension is the "bracketing" out of known risks or uncertainty. Suspension involves a 'leap of faith' which enables a person to move from interpretation to expectation (Möllering, 2001). According to Möllering:

> Trust can be imagined as the mental process of leaping – enabled by suspension - across the gorge of the unknowable from the land of interpretation into the land of expectation (Möllering, 2001, 412).

Möllering (2006) presents a detailed theory of the various bases from which trust can be built, discussing multiple "good reasons" which further our understanding of the "land of interpretation". However he argues that 'good reasons' in themselves do not necessarily always lead to trust, and that it is the suspension of uncertainty and acceptance of vulnerability which defines trust (Möllering, 2006, 110-111). This leads him to suggest the following definition:

> Trust is an ongoing process of building on reason, routine and reflexivity, suspending social vulnerability and uncertainty *as if* they were favourably

> resolved, and maintaining thereby a state of favourable expectation towards the actions and intentions of more or less specific others (Möllering, 2006, 111).

Möllering (2006) argues that trust may develop from any combination of three bases: reason, routine and reflexivity. 'Reason' as a basis for trust is presented by Möllering (2006, 46) as a rational choice based on either a cognitive or affective assessment of the trustworthiness of a potential trustee. Impressions of trustworthiness of the potential trustee might be informed by multiple factors including assessments of the incentives for the potential trustee to honour that trust, perceptions of their motivations in acting, their competence and their character (Hardin, 1996; Möllering, 2006). However, according to Möllering reason alone is limited as an explanation of trust because it assumes that trusting is always a consciously informed rational choice. Moreover, he points out if trust is based on the knowledge of the trustworthiness of a potential trustee then this in itself removes the necessity of trust; if you know someone will act in a certain way then trust is unnecessary. Finally, he points out that 'reason' is not a complete basis for trust because it does not take into account the development of trust overtime and implies that whether trust is placed or not is largely dependent on characteristics of the trustee rather than the trustor.

The second basis for trust discussed by Möllering is "routine" or "taken-for-grantedness" (2006, 52). Möllering argues that trust can be based on familiarity with social rules and practices, rather than a conscious assessment of the trustworthiness of a particular individual. In outlining this argument (2006, 55) Möllering draws on theories (such as Zucker, 1986) which emphasise that trust is facilitated by the daily enactment and (re)construction of social norms, practices and expectations of social conduct. As Möllering puts it:

> "A trusts… the trustee B in a certain matter because it is natural and legitimate to do so and 'everybody would do it'. For similar reasons, trustee B will honour the trust" (Möllering, 2006, 61).

In contrast to the rational basis for trust here trust comes from the context of social expectations, rather than from the characteristics of the potential trustee. Möllering's presentation of 'routine' as a basis of trust also incorporates Giddens' (1990) discussions of trust in abstract systems which, he suggests are maintained through the convincing performance of representatives of that system respectively. He also incorporates Luhmann's (1979) discussion of the relationship between familiarity and trust. However, understanding 'routine' as the only basis of trust does not explain how social norms are created in the first place or how actors come to accept the ignorance and vulnerability characteristic of trust.

The third basis of trust discussed by Möllering (2006) is that of establishing trust as part of a reflexive process. Möllering argues that trust develops between two actors from initially acting "as-if" they trusted, to a genuine trust based on mutual experience of expectations of each other being met (Möllering, 2006, 94). He also draws on Giddens' (1994) theory of "active trust" to argue that gaining the trust of another person has to be worked at through "open communication" and sharing of information, leading to increasing familiarity, and hence trust (2006, 99). In summary, he states:

> Trust is a matter of reflexivity in that it often needs to develop gradually in processes which, once they get started, may be self-reinforcing but require active agency, too (Möllering, 2006, 102).

Möllering (2006) goes on to propose that all three bases (reason, routine and reflexivity) act in various combinations as spring boards for a 'leap of faith', in which the trustor suspends uncertainty and trusts, i.e. adopts particular expectations of the trustee. Whether these expectations are met, clearly then informs future processes of building trust, as Möllering suggests, the "land of expectation" becomes the "land of interpretation" (2001). However, because Möllering (2006) is mainly interested in discussing how trust comes about, he does not offer an equally detailed consideration of the sorts of expectations ultimately made in trusting.

In the analysis of professionals' organisations of diabetes care, and patients' experiences of this care, which I will present below, I will be concerned with the consequences of different sorts of trust. Möllering's (2006) theory suggests how trust can differ in terms of its basis, but trust may also differ in terms of who we trust, and to do what. Hence, I have also chosen to draw on aspects of Sztompka's (1999) theory because he reflects on the expectations which trust can entail in greater detail than Möllering (2006). The area of Sztompka's work that I will draw on focuses on the 'land of expectation', the forms which trust takes once the 'leap of faith' has been taken, it provides a useful framework for thinking about differing sorts of trusting expectation (1999).

Sztompka

Sztompka (1999) suggests that trust means making a choice based on an assessment of the potential trustee's trustworthiness, which is also influenced by the trustor's personality and culturally informed predisposition to trust. Möllering (2006, 23) criticises Sztompka (1999) for over emphasising rational deliberation as the basis of trust for reasons I highlighted above. I agree with Möllering's (2006) criticism, but whilst Sztompka (1999) may have a less rounded conceptualisation of the bases of trust, in his theory of trust he presents a useful way of conceptualising trusting expectations.

Sztompka (1999) observes that trust is always placed in people not in natural objects. As stated above, trust involves accepting vulnerability based on positive expectations of the actions of another person. Hence, trust is placed in the independent agency of that individual to act in a favourable manner. So, trust can only be placed in people who have some degree of freedom to act, rather than natural objects which do not have that agency (Sztompka, 1999, 21). However, Sztompka does go on to assert that trust can be placed in social objects (such as cars or clinical guidelines) which act as a proxy for the people who created them.

Rather than making a clear distinction between trust in abstract systems and interpersonal trust as other theorists such as Giddens (1990) do, Sztompka suggests

instead that we conceptualise trust as a series of layers relating to differing social relationships with the person entrusted. He suggests that:

> There are in fact gradual, expanding, concentric circles of trust, from the most concrete interpersonal relations, toward more abstract orientation toward social objects (Sztompka, 1999, 42).

In the narrowest radius we have trust in those socially the closest to us, such as friends and family and then moving out from there, people we know personally (Sztompka, 1999). The widest circle of trust in Sztompka's (1999) model includes people with whom we believe we have something in common or whom we trust on the basis of the social categories they fall into (for example trusting women more than men). This widest circle also includes trust on the basis of social roles such as a doctor or a priest. Outwith this there is trust in institutions such as schools and universities, or trust in the procedures such as peer review.

Sztompka (1999) also makes a distinction between primary and secondary targets of trust. The former are actors who, for whatever reason are directly trusted, the latter are actors who are trusted as part of the process of placing one's trust in someone else. For example, if a trusted doctor testifies to the care and competence of her colleague, a patient might be more likely to trust that colleague. In this instance the original doctor is a secondary target and the colleague is the primary target. Hence, trust in a person or social object might be built up informed by multiple factors from the various layers outlined above.

In addition, to who we trust, what we trust them to do also varies depending on the social relationship and context. Sztompka delineates three varieties of expectation involving the acceptance of differing degrees of risk or vulnerability on the part of the trustor, and relating to the differing concentric circles of trust (1999, 51). "Instrumental" trust involves the expectation that the trustee is competent and efficient. For example, instrumental trust is present in team work where individuals are each carrying out separate coordinated tasks to achieve a shared goal (Sztompka, 1999, 64). Each person

expects the other to perform the set task efficiently and competently. This is also the kind of trust that one might have in "science as the best method of reaching the truth", where trust is an expectation that institutional practices and procedures will produce trustworthy evidence (Sztompka, 1999, 44). "Axiological" trust is the belief that another will act on shared moral values. Sztompka (1999, 44) suggests that this form of expectation is exemplified by the case of a jury where members expect each other to act with moral integrity. I will contend that it is also exemplified by the expectation that the clinician will refer a patient appropriately and for the right moral reasons. Finally, "fiduciary" trust involves the belief that the trustee will place the interests of the trustor before their own, acting on their behalf and "caring" (1999, 64). Sztompka uses the examples of a climbing expedition and a team of surgeons working together on a complex operation to illustrate this form of trust. Essentially it involves an expectation that the trustee will take the interests of the trustor as the basis of their actions rather some other self-serving motivation. Instrumental, axiological and fiduciary expectations can be viewed as part of a scale from the fiduciary, involving the greatest risks and hence the greatest level of commitment, to the instrumental which involves least risk and hence a lesser 'bet' and usually relates to less close social relationships (Sztompka, 1999, 51- 54).

Conclusion

In the following chapters I will draw on both Möllering's (2006) theory of the bases of trust and Sztompka's (1999) delineation of the different sorts of expectation which that trust can entail. I will show that the distinctions these theories make between differing bases and expectations of trust are useful in understanding the organisation of diabetes care amongst professionals, the ways in which patients' experience that care, and the influence of this on their perceptions of their condition and their role in managing that condition. In the next chapter, I will continue to discuss the organisation of diabetes care within each case study which I began in chapter four. In particular, I will show that professional identities and jurisdictions, trusting inter-professional relationships, and

trust in clinical evidence influence the particular way in which diabetes care is organised.

Chapter 5: Organising care across professional boundaries.

Introduction

Chapter four focused on the organisation of diabetes review appointments within the general practices in each case study. It noted that there were both similarities and differences between the cases in the way in which this central aspect of diabetes care was organised. All three operated a patient recall system and had chosen to run clinics to provide structured reviews, separating diabetes care from everyday general practice. I also argued that the particular approach to organising these diabetes clinics could be partially explained in terms of the 'ethos' of general practice espoused by the professionals at each, including differing interpretations of 'holism' and 'continuity' of care.

This chapter will be divided into two parts. The first will consider the organisation of diabetes services with professionals based outwith each general practice and the factors which appeared to mediate referral patterns to these 'external' professionals. The second will then further consider the organisation of the diabetes clinic within each practice, focusing on what evidence clinicians drew on to inform clinical practice and which clinicians provided diabetes care. Across these two parts I will argue that the implementation and meanings attributed to policy instruments and, their influence on diabetes care, exists in a dynamic relationship with existing inter-professional identities and relationships of trust.

Organising Care with professionals based outwith the practice

Diabetes care in primary care involves multiple professionals who may be based outwith the practice itself. For example, dieticians and podiatrists are often based outwith the practice, and diabetes specialist nurses (DSNs) may act as intermediaries between primary and secondary care. Which professionals were considered part of the wider

'primary care diabetes team' by the general practice clinicians differed between case studies. Indeed, in some cases, the professionals considered part of the primary care team by the general practice staff were based in secondary care and presented themselves as principally secondary care clinicians at interview. This was particularly true of the DSNs in all three cases.

In this section I will describe patterns of referral between the various professionals in each case study and argue that these reflect local, historical organisational precedents and the role played by personalities and relationships between the health professionals involved.

Silvenea

Since he started work at the practice in 1988, Dr Harrison said that diabetes care at Silvenea had been organised as "shared care with the hospital". However, he commented that in the past the:

> Hospital didn't seem to have any great interest in type 2 diabetics, despite the evidence… [the doctors] didn't really seem to know how tightly blood [glucose and] blood pressure for diabetics [should be controlled]...There didn't just seem to be the oomph from the hospital to do very much about it.

For these reasons, he told me, his former part-time partner had started the practice-based clinic and had written a template for diabetes care in 2003. However, it seems likely that this was also partly prompted by the practice's participation in the RCGP accreditation scheme[9] at that time.

Dr. Harrison explained that he referred only particularly complicated cases, such as pregnant women with diabetes, to the consultant diabetologist based in the city and

[9] General Practice Accreditation was a voluntary scheme run by the Royal College of General Practitioners before the introduction of the nGMS contract and was a for-runner of many of the organisational targets subsequently incorporated in QOF. *rcgp.org.uk/staging53/.../practice_accreditation.aspx* (Accessed 2nd September 2008).

referrals were very rare. This was partially because he considered it inconvenient for patients to have to travel 100 miles to the city hospital. So, the locality's DSN, Kiera, and a general medical consultant based at the rural district general hospital in Oldtown provided the main secondary care support for diabetes at Silvenea. The practice relied predominantly on Kiera (with the support of a registrar or a general medical consultant) to introduce patients with type 2 diabetes to insulin when they needed it. Yet, whilst Dr. Harrison was not confident prescribing insulin himself, he criticised the hospital for not always introducing insulin as early as he thought necessary. He did not know why this was the case, which suggests that, from his perspective, communication with Kiera was perhaps not as open as it could be. In contrast, the district nurses and Dr. Crawford at Silvenea, said that they would speak to Kiera if they had any queries and Kiera commented that she felt confident they would get in touch with her if they had any concerns.

Professionals at Silvenea referred patients to a podiatrist who, although based at Oldtown Hospital, ran a clinic at the practice once a month and told me that he was included in practice meetings when anything to do with podiatry was on the agenda. He had also provided training in foot screening to the Health Care Assistant. In contrast, the Silvenea GPs told me from my first introductory visit that they did not refer to the community dietician who carried out clinics at other practices in the area. This seemed to be a sensitive issue and the most Dr. Harrison would say about the matter during my fieldwork was that he thought it was best to "work around" health professionals who did not "pull their weight". Dr Crawford explained that if they felt they needed the specialist knowledge of a dietician "then we'd refer to the dietician at the hospital". Kiera, the DSN, was aware of the situation and offered a little insight into it:

> Well, there was a bit of an attitude to the dietician, shall we say…
> **HM: Is that because of their characters?**
> Yes. I would say. And she's a bit more forward thinking cos she's straight out of university.

Personal clashes of character, approach, and expectations of the dietician's role appeared to influence the relationships and referrals between the Silvenea GPs and the dietician. Kiera went on to emphasise that she viewed communication as particularly important in facilitating the coordination of care. When she started her post as DSN three years earlier she thought that the relationship between primary and secondary care in the area had been poor:

> Previously, the diabetes nurse here was only 15 hours a week, with the result there obviously wasn't a lot of communication between the GPs and when I got the post, I had a meeting with the GPs and the [general medical] consultant just to open up lines of communication… three years down the line, it's still ongoing but there's certainly a better relationship.

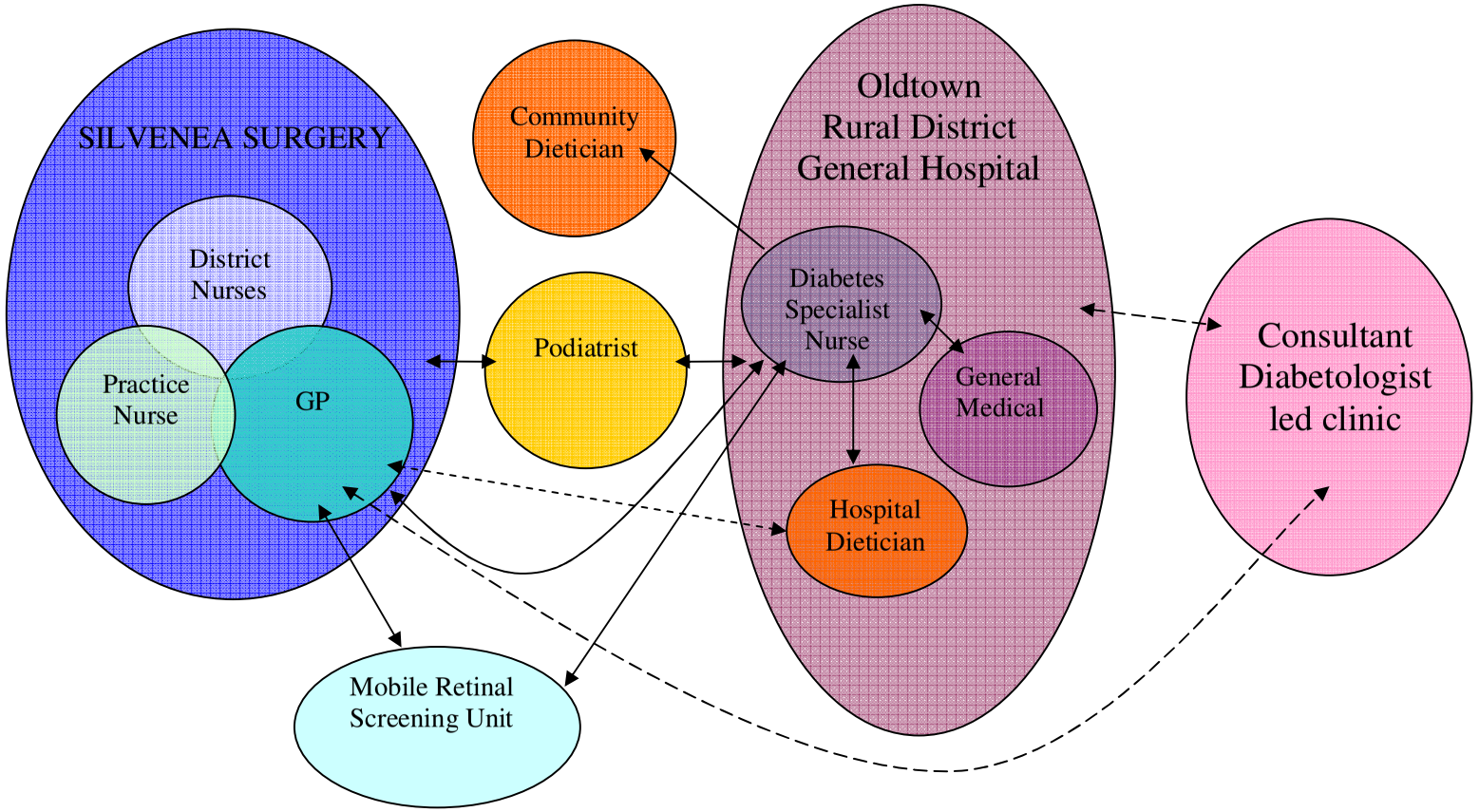
Despite this previously poor communication she felt she had with primary care in general, Kiera said that Silvenea professionals did not fit into this generalisation. She described Silvenea as a "good practice", because she viewed the professionals to be "good at communicating". She did not explicitly define what being "good at communicating" entailed but did go on to comment that she expected the health professionals at Silvenea (and she named the district nurse in particular) to contact her if they had "problems". She expected and trusted that the professionals at Silvenea would know boundaries of their clinical knowledge and to ask for advice when appropriate.

Meeting expectations associated with a professional role and "good communication" emerged as factors which facilitated inter-professional working. Moreover, it appears that professionals meeting expectations of their roles, and having "good communication" could act as a reflexive basis for trust to be built up over time (Möllering, 2006). In contrast, experience of expectations not being met could undermine trust and hence act as a barrier to inter-professional referrals. Role expectations in themselves appeared to be taken-for-granted. However, trust, or a lack there of, was also influenced by assessments of the potential trustee's character, as was the case in Dr Harrison's lack of trust in the dietician. Inter-professional trust entailed expectations that the professionals recognise the same professional boundaries and provide appropriate care. To draw on

Sztompka's (1999) delineations of trusting expectations Kiera can be said to have instrumental and axiological expectations of the primary care clinicians at Silvenea.

To summarise the organisation of diabetes care at Silvenea I have included the following diagram. This represents which professionals were involved in type 2 diabetes care, with the arrows indicating who referred to whom. Dotted lines indicate a rare referral and the larger circles indicate with which institution the professional was most closely associated. Over-lapping circles indicate when professionals worked particularly closely, perhaps discussing patients and sharing decisions on care. A diagram will be provided for each case study in turn to illustrate the differences in diabetes service organisation between the cases.

Organisation of diabetes care at Silvenea



Corryhabbie

Until 2000 Corryhabbie referred all type 2 diabetes patients to the consultant-led diabetes clinic in the city. As I noted in the introduction, British general practice has been more and more involved in diabetes care since the 1990s, hence Corryhabbie was somewhat unusual in starting to provide this service so late. I was told by professionals that this was a result of the historical relationship between primary and secondary care in the region which. For example, Dr. Shore explained how care had been organised when he started work at Corryhabbie in the 1980s:

> Virtually all diabetic work went to [secondary care]… the clinic was building up its empire… basically the more patients, the more funding they could attract… And I think a lot of it was [because of] the attitude as well, [that] these specialist conditions need to be managed by specialists in hospital.

This had not just affected Corryhabbie. As a result of what was termed the "hospital hoover" by various professionals, there was a generally held perception amongst both primary and secondary care clinicians that GPs in the area had become "deskilled" in the care of diabetes. For example, at a community health partnership (CHP) meeting organised by the diabetes MCN, one GP commented that he was the GP lead for diabetes at his practice, but that if the nurse with specialist training left he would not have the knowledge to continue. Dr. Andrews told me that, in the late 1990s, there had been some attempts at Corryhabbie to move towards a shared care arrangement with patient held records, but this idea had collapsed due to a general lack of support from secondary care.

Professionals at Corryhabbie told me that their diabetes clinic was not created in direct response to any particular health policy, but resulted from the initiative and direction of one particular practice nurse. Since then the tables had turned in health policy and secondary care was no longer perceived as trying to provide all diabetes care. Rather, Vicki and the two GPs I interviewed perceived increasing "pressure" from secondary

care as another factor which had driven the establishment of the practice's diabetes clinic.

Indeed, early on in my two weeks of fieldwork, the movement of patients back into primary care emerged as a core concern of the health professionals at the practice. The professionals at Corryhabbie believed that secondary care was discharging too many patients back into primary care too suddenly. This, they suggested, was because secondary care was overstretched and was not considering whether general practice had the resources to deal with so many patients. As Vicki put it, professionals in secondary care were trying "every trick they know" to get patients into primary care. Dr Andrews described patients "turning up at the practice" with no letter of discharge, "saying that the consultant said that they would be seen with us from now on". This situation was seen as driven by secondary care rather than by the Health Board or national policies, as the following quote from Dr. Shore exemplifies:

> It certainly became Health Board policy that they would like to see more diabetic care in primary care, but the clinic itself was getting very keen to discharge people… because their workload was just getting quite unmanageable.

At the community health partnership (CHP) meeting, Corryhabbie professionals attempted to complain to the presenting consultant diabetologist about the number of patients being referred out of the City clinic to Corryhabbie. The consultant responded that there was no policy of routinely discharging patients into primary care, and closed the subject by using the patients as scapegoats and joking that "patients can be terrible people". The tension between primary and secondary care was obvious, with each side accusing the other of attempting to off-load work.

The DSN's perspective of this disagreement between primary an secondary care was also quite different from that of the primary care professionals. She observed that, because of the increasing incidence of diabetes, the numbers being cared for in secondary care had been stabilised, rather than reduced, by offering care in primary care

and complained that there seemed to be a general misperception in primary care that secondary care now had fewer patients. This seems quite likely; however, the primary-secondary care tensions remained.

The DSN ran a clinic at the local community hospital in Corryhabbie once a week. However, she was perceived by the clinicians at Corryhabbie to maintain a secondary care focus and was viewed as quite peripheral to the practice. Vicki commented that:

> There isn't really any liaison between her and the practice. Although she's a primary care employee, she actually comes over as secondary care, because she's based at the city hospital.

Dr. Andrews explained her perception of the DSN's work:

> The DSN comes out once a week and apparently sees some of our patients who are on insulin but the communication/ co-ordination is not as good as it should be with that.

Dr. Andrews' somewhat uncertain description of the DSN's work evidenced her lack of involvement with the practice-based team. This was further emphasised when it became apparent in my interview with Dr Shore that he was unaware that the DSN was available to refer to, even though she had been in post for over 15 years.

In our interview, the DSN, Patricia, presented her own job as "filling the gaps" between secondary care appointments for patients who were having problems managing their diabetes or who were just learning to administer insulin. She consulted with these patients in the local community hospital. On the whole she said that she saw patients whose care was based in secondary care and very rarely received referrals from general practice. She commented that while there was the "facility" for her to receive referrals from the practice, "they wouldn't ask me to see patients they are seeing themselves". She seemed to overlook any potential for expanding her role in the community, for example, by initiating insulin with patients based in general practice. Overall, the DSN seemed to be distant from primary care, and did not take regular referrals from Corryhabbie.

In addition to the DSN, a dietician, Jane, also provided care in the community, receiving referrals from the GPs and Vicki, who described her as "bright and enthusiastic". Like the DSN, Jane consulted with patients from Corryhabbie at the local community hospital. However, she said she would rather be based within the practice itself in order to access more information about the patients she was seeing, either formally through their computerised records or informally through conversations with Vicki or their GP, but, there were no free consulting rooms for her. Whilst Jane both knew Vicki from shared training and would phone her if she had any concerns, but she pointed out that Vicki was only available two days a week, and this did not always coincide with Jane's Corryhabbie clinics. The dietician also discussed communication and referral difficulties she had with Patricia the DSN. In other areas where she worked she explained she would informally discuss patients, whom she thought needed to be seen to have their drugs adjusted, with the DSN. However, Patricia was not willing to have such informal communications or arrange appointments to see patients on the recommendation of the dietician. Patricia insisted that the patient should follow the official pathway of being referred back to their GP, who could refer them on to her. Whilst the dietician believed informal communication with the unnamed DSN facilitated care elsewhere, Patricia's insistence on formal procedures slowed and stilted care provision. In addition, it created a sense of division; Patricia seemed to use official procedures to ensure the maintenance of professional boundaries and to control her work-load. This meant that the dietician was somewhat isolated from both the DSN in the community and the practice. Such difficulties of communication have the potential to present a barrier to the provision of coordinated care, as they were already stilting quick referrals.

Community podiatrists also provided care at Corryhabbie, but, unlike the dietician, they used a treatment room within the practice. I was told by various professionals that podiatry was understaffed and, according to Vicki, it took eight months before a patient she referred was actually seen. Hence, she advised patients to attend private clinics if they could afford it. She went on to suggest that she thought that the service would be vastly improved if there was a community podiatrist specialising in diabetes. This was a

view which was echoed by the podiatrists, who were well aware of the difficulties they had trying to manage what they told me was an increasingly large case load.

Given the long waiting times for a podiatry appointment, it was even more important that referrals were well organised. The podiatrists highlighted the importance of communication between professionals by telling the following story of a patient they had seen at Corryhabbie:

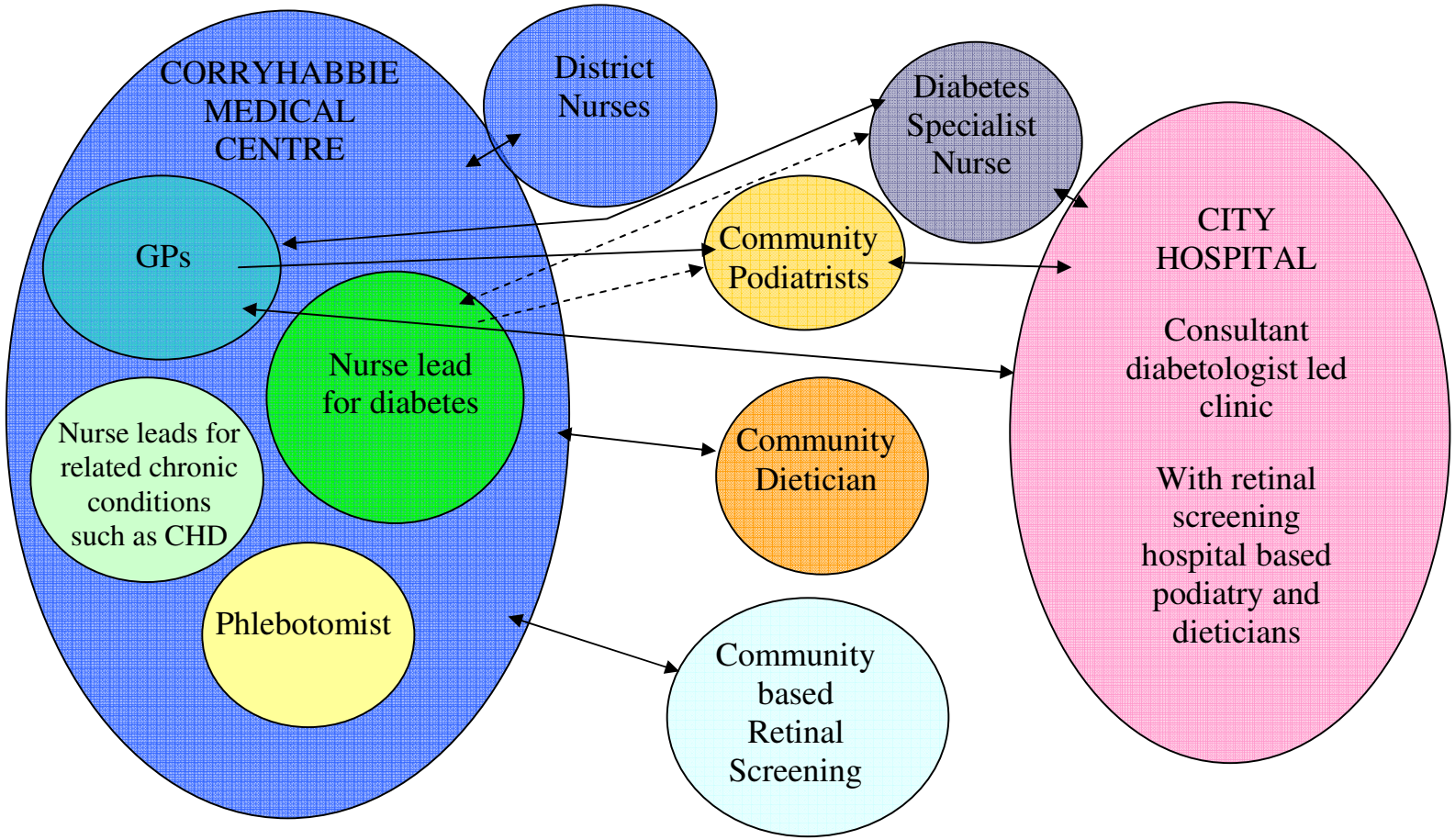
> Not long ago, a GP referred this man who was having problems… [with] hard skin. He went on the waiting list lower down than he should have done. Had the doctor said that he had ulceration in the past, circulation problems, we would have seen him a lot sooner. So, he's lost 2 toes and we think if we'd caught him sooner, he wouldn't have… the doctor's excuse was he didn't realise how long our waiting list was… Now, if you work here for several years, if you don't know roughly the waiting list of folk working in your own practice, then I would think it was time you… found out… The practice manager here knows how long our waiting time is… I mean, we talk to most of [the GPs], most of them know… Other GPs will come through and ask questions... That's how it should be… You should all be asking each other… It might just be in the corridor or the staff room but that conversation, it might only be 2 minutes, but that's just as important as anything else.

The story above highlights once again the importance of "good communication", which Silvenea's DSN emphasised. This includes informal communication between health professionals, to support appropriate divisions of labour, referral practices and coordinated care. Communication and negotiations of care on a daily basis were not just about professional jurisdiction, but defined informal divisions of labour and informed appropriate referrals. Communication was an essential factor to providing coherent care but could be hampered by various factors of organisation and personality: being located elsewhere limits the opportunities for face-to-face contact and informal communication which could also limit appropriate referrals, but personalities and differing understandings of professional roles could also limit communication and referrals.

Again, I would argue that communication and mutual recognition of professional roles emerge as bases for trust, or a lack thereof. Moreover, primary care professionals'

suspicion of the motivations of secondary care in referring patients back into primary care, in a manner which they claimed was inappropriate, also limited trust. In the case of the podiatrists above, instrumental expectations that other professionals would act efficiently and competently had been disappointed as a result of poor communication and may have undermined bases of future trust. Similarly, primary care clinicians' trust based on the perceived motivations of their secondary care colleagues had come into question because they appeared to be acting out of their own self-interest, rather than the interests of the patient. This could be traced back to the history of secondary care previously wanting to provide all diabetes care in hospital because of the financial rewards associated with health policies from the 1980s onwards.

Organisation of Diabetes care at Corryhabbie



Strathfinella

Like Silvenea, there was a long history of providing services for type 2 diabetes in general practice at Strathfinella. The practice had run a diabetes clinic for over twenty years, which had until three years earlier, been run by a now retired GP. This was Dr Sinclair, who had also worked in the secondary care clinic. When patients needed to start using insulin or developed disease complications they were referred to the clinic at Braeburn Hospital. The Braeburn clinic included a consultant diabetologist, DSN, podiatrist and dietician. Despite being physically based within secondary care, the DSN, podiatrist and dietician at Braeburn were included by the professionals at Strathfinella as part of their 'primary care diabetes team'.

The professionals at Strathfinella were generally positive about the individual clinicians based at the Braeburn diabetes clinic. For example, Dr. Rosalind Scott commented:

> We have a very good, consultant team, and a very good, diabetic specialist nurse, so… I find myself just phoning, and I know Erica phones the DSN, quite a lot of the time, just to ask for information… You get the information to help your patient but also I think, I'm better educated and I love that ability to have a bit of communication with professional colleagues who are more specialised in that field. I think that's great cos you don't get that from guidelines, we've got advice and guidance.

Dr. Scott focuses particularly on the DSN and emphasises the value of being able to communicate easily and ask for advice over the use of clinical guidelines. This supports observations by Gabbay and le May (2004) that "collectively constructed mindlines" may be preferred to clinical guidelines in primary care. Inter-professional networking and personal communication remain key to day to day practice. This view was shared by the DSN, Sarah:

> Thinking about Strathfinella practice, I know if I've got to put somebody onto insulin, I'm very happy for Erica to supervise the first injection and perhaps do the interim alteration and I know with confidence that she will refer back to me if there is a problem, and similarly with Dr. Scott… It's about the individuals within the practice. That's what seems to make the

> biggest difference and how well we are able to communicate with each other for whatever reason.

The DSN had "confidence", or trust, in both the clinicians' ability at Strathfinella, and their judgement of the boundary of their knowledge and professional jurisdiction. This was supported by personal knowledge of the clinicians involved. Sarah had been the DSN based at Braeburn Hospital for 13 years and, through the "outreach clinic" she used to run in general practice, she had come to know Dr. Scott. Similarly, she knew Erica because she had been one of the first students on a diabetes training course which the DSN had been involved in providing. This personal knowledge built up through communication, shared experiences and mutual experience of receiving appropriate referrals provided a basis for trust between these individuals.

Similar relationships were evident with the dietician and podiatrist at Braeburn. The dietician told me that the hospital team's "confidence in practice's ability and communication" had been enhanced by primary care clinicians' participation on their training courses. The podiatrist expressed similar confidence in Erica in particular:

> I met Erica when she did that course... when she rings about a patient… you know exactly what you're getting through the door. So it's really benefited communications with practice nurses who've done that course, you know.

The training course which Erica had attended had served two purposes: it meant that the primary and secondary care professionals were assessing their patients by the same criteria, leading to appropriate referrals, and it meant that they met each other face-to-face, both of these factors had facilitated better communication and coordination of care. At Strathfinella the primary and secondary care professionals had established personal relationships which enabled them to both negotiate jurisdictional boundaries in everyday care and establish a mutual recognition of their professional boundaries. Not only does Sarah expect patients to be referred to her if there is a problem, but Dr. Scott and Erica are happy to turn to her specialist knowledge. These were reciprocal instrumental

expectations (that patients will receive competent care) and axiological expectations (that colleagues will act in the best interests of patients and refer appropriately).

However, Sarah went on to comment that this relationship had not been effectively established at all of the practices in the area; indeed her presentation of primary/secondary care relations generally was quite different to that of the specific case of Strathfinella:

> The relationship between primary and secondary care in terms of diabetes seems to have a lot of tension… on the one side, you've got general practice and on the other side you've got secondary care and in between is a huge chasm…
> **HM: Why is that?**
> I think it's about the personalities involved and it probably is historical as well… I'm aware that from a general practice point of view, there's a perception that the money's always gone to secondary care and in the past that may well have been the case. And now in secondary care, it's always, well, the money always goes to general practice, and there's a bit of resentment about that. Sometimes it's about personalities, certainly in the more rural areas… [some GPs] want to be an empire builder. And that then affects, their relationship with other health care professionals, [they have the attitude] that… 'we don't want your input, we can do it all here'. And so people are shut out, pushed out and that then affects the relationship.

When speaking in generalities Sarah presents a great divide between primary and secondary care professionals who lack the cooperation and trust which she described in the specific case of Strathfinella. Whilst the archetypical relationship between primary and secondary care professionals was presented in one way, the daily interaction between the two in the case of Strathfinella is presented quite differently, reflecting the day to day negotiation of care with particular professionals. Notably, the problems she highlights from "personalities" in primary care in general (poor communication and a lack of recognition of professional boundaries, knowing when it is appropriate to refer a patient on, not fulfilling expectations of their professional role) are the direct opposites of the factors which she also claimed facilitated coordination of care with the professionals at Strathfinella. Interestingly, Sarah also highlights that the stereotyped divisions have been enhanced, or drawn along the lines of previous health policies,

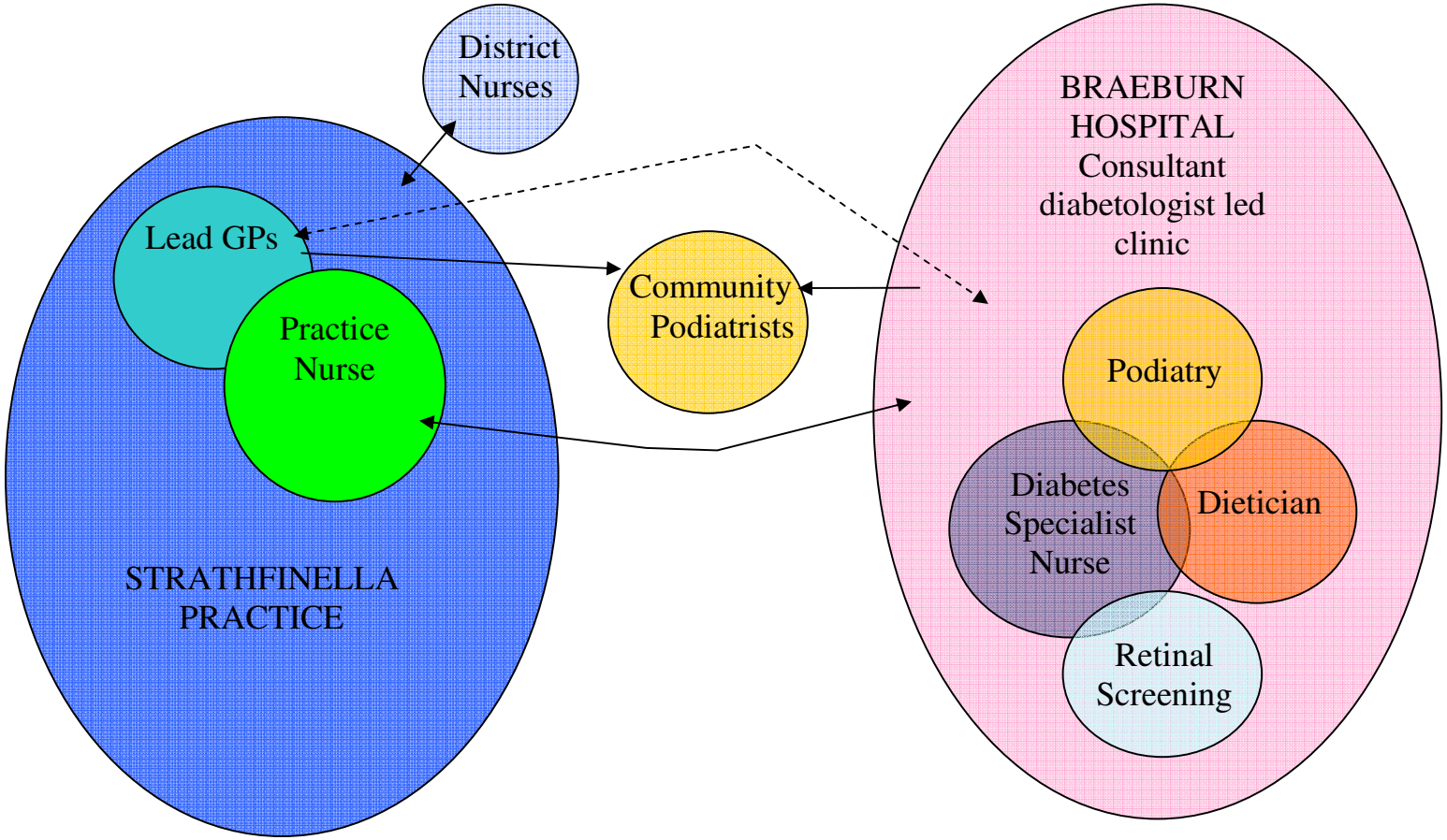
which have created “resentment” by redirecting resources to and from each sector in the past.

Like Sarah, when speaking in generalities Dr. Scott presented a negative outline of the general organisation of care between primary and secondary sectors:

> Sometimes patients are only seen by Sarah for follow up and sometimes they’re only seen by a doctor, and sometimes, I’m not awfully clear about what Braeburn are doing... [for example carrying out investigations which have already been done in primary care]. I think the problem is largely a poor understanding of how primary care works… They don’t know what we do, they don’t know anything about the GP contract, they’ve no idea about what kinda services we can deliver… and actually that irritates the knickers off me I have to say because it just confuses the patient, wastes resources, and what’s the point?

Like Sarah, Dr Scott complained of poor communication generally between primary and secondary care and a poorly defined boundary of professional jurisdiction between the two sectors. So whilst at Strathfinella the relationship between the practice and ‘external’ diabetes professionals was couched in terms of primary/secondary care boundaries, these boundaries were overcome by personal relationships and mutual experience of referring patients to each other. Personal relationships between the professionals which had developed over time, communication, and a mutual understanding of professional jurisdictions, all acted as bases for trust. This trust involved both instrumental and strong axiological expectations that colleagues would provide competent care to patients, and so, these expectations appeared to facilitate referrals.

Organisation of diabetes care at Strathfinella



Summary

Diabetes care involves many health professionals based in different locations. On the one hand, which clinicians are involved is obviously influenced by questions of population and geography. For example, there is no consultant diabetologist at the rural general hospital near Silvenea as there is not a large enough population of patients to support this post. However, from the data presented above it is also apparent that the relationships between individual professionals can act as either facilitators or barriers to the provision of services across traditional professional boundaries. Local precedents of service organisation and the historical influence of past health policies defined the background to current organisations of care, and informed stereotyped perceptions of professionals from 'other' sectors. In addition, personal relationships, communication, and a shared understanding of professional roles could facilitate the coordination of care across traditional professional boundaries. This was partly dependent on the individual personalities involved, but also, mutual knowledge of the clinical ability and tasks undertaken by different professionals.

Frequent "good" communication, (including impromptu informal discussions), shared experiences of training, and experiences of patients receiving appropriate care and referrals, all acted as bases for trust across professional boundaries. This trust involved the dual expectations that other professionals would provide competent care, and refer patients as and when appropriate, recognising the same division of labour and jurisdictional boundaries as oneself. Experience of these expectations being met then provided a basis for further trust.

In the section above I noted that Sarah, the DSN at Strathfinella, identified previous health policies which had directed resources to or from primary or secondary care as a source of "resentment" and tension between the two sectors. Similarly, at Corryhabbie it was the legacy of health policies which encouraged secondary care clinics to 'empire build', which GPs used to explain the practice's previous lack of involvement in

diabetes care. In the next section I will consider how perceptions of two current health policy instruments, the Quality and Outcomes Framework (QOF), and Managed Clinical Networks (MCNs) were both informed by, and informed perceptions of, the 'other' across general practice, allied health professionals and secondary care. I will then move on to focus on the influence of these policies on the organisation and delivery of diabetes care within the general practices.

The influence of Health policy in local contexts

Managed Clinical Networks

As outlined in the introduction, one of the initiatives of Scottish health policy has been the establishment of diabetes managed clinical networks (MCNs). MCNs were first defined in a Management Executive Letter in 1999 as:

> Linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and Health Board boundaries, to ensure equitable provision of high quality clinically effective services throughout Scotland. (Carter and Woods, 1999)

MCNs were intended to promote collaboration by bringing together clinicians, managers and patients involved with a particular condition to define the structure of care in each Health Board and improve coordination between points of service delivery. MCNs also have the remit of ensuring consistency of standards and quality of treatment across their Health Board and this has been met partly through the publication of local clinical guidelines, which are "based on a documented evidence base", such as SIGN guidelines (Jones and Armstrong, 2002). Each MCN is also audited by NHS Quality Improvement Scotland. So, MCNs act as both policy instruments, promoting inter-professional collaboration through their membership, and implementers of policy instruments, such as local clinical guidelines. In this section I will briefly discuss how the diabetes MCN in each case study's Health Board was perceived by the health professionals providing care.

Kiera, the DSN for Silvenea, had attended meetings with their Health Board MCN and was keen that Oldtown Hospital would be "kept in as part of the team". At Silvenea the nurses referred to MCN guidelines, but Dr. Harrison explicitly stated that he felt the MCN was not useful for his work:

> Well, what do I want the managed clinical network for? I want, [for example] access to a renal physician for patients who've got renal failure. Now, the rate of renal failure is… one patient every five years. Now, if you give me some information about your managed clinical network today, it's gonna be of no value to me in five years.

Whilst the DSN was keen to be involved, Dr. Harrison saw the MCN as irrelevant to his experience of providing care at Silvenea. He told me that he had been involved with developing the MCN guidelines at an early stage, but had become very disillusioned with the whole enterprise as it seemed to merely repeat what had already been written elsewhere.

In addition, some of the initiatives of the MCN were perceived as inappropriate, top-down policies. For example, the MCN in Silvenea's Health Board had introduced a mobile retinal screening unit, funded by the Remote and Rural Areas Resource Initiative (NHS Quality Improvement Scotland, 2004; NHS Quality Improvement Scotland, 2007). The DSN attributed this change directly to the Scottish Executive's attempts to improve care in very remote and rural areas, but when appointments were missed it was very difficult to know when the unit would be returning to organise another appointment. It was therefore more inconvenient than referring patients to receive screening at the Oldtown opticians, as they used to. Although theoretically an appropriate idea, the mobile screening unit had not taken into account existing local practices for rearranging appointments and flexibility in access.

Whilst the MCN was seen as an opportunity to be involved in service planning by the DSN, she also viewed it as implementing top-down initiatives like the mobile retinal screening, which were not always well considered. At Silvenea Dr Harrison considered

the MCN irrelevant and unhelpful whilst the other professionals claimed to be unaware of the MCN itself but referred to the MCN guidelines as "the Bible" when I showed them the document.

At Corryhabbie, the existing relationships and tensions between primary and secondary care, which I described above, were particularly apparent in professionals' perceptions of the MCN and its initiatives. Whilst the DSN praised the MCN for bringing structure to the service and taking forward their request for a new post of DSN for adolescents to the Health Board, the primary care professionals I spoke to were more suspicious. For example, Dr. Andrews commented that:

> I think there has been problems in that it has had a bit of a secondary care outlook on life rather than a primary care outlook on life… I think the MCN has been created to ensure that patients are moved out into primary care because secondary care can't cope, although I appreciate they would say – and I'm sure they're right to some extent – it's to improve overall care, because they will get better care probably with us than they would in the City…
> **HM: Do they involve GPs in decisions made within the MCN?**
> There have been GP representatives. I have been to various meetings… and that's what I tend to have to say – yes, but wait a minute, look at this from primary care.

National policies of moving diabetes care into primary care, which were being promoted by the MCN, were given significance within the local context, and were perceived to advantage and support secondary care. Unlike Silvenea where the MCN was viewed as an external organisation closely associated with the Scottish Executive, the MCN at Corryhabbie was viewed as a tool of secondary care.

At Strathfinella, Dr. Scott and Erica considered the MCN to have made a clear difference to diabetes services; for example, through the establishment of Local Enhanced Service (LES) rewards for diabetes and through the MCN clinical guidelines. They had also been involved in helping the MCN devise those guidelines and in various projects initiated by the MCN manager. Whilst Erica and Dr Scott felt that the MCN was

generally improving clinical practice locally, the health professionals I spoke to based at the hospital felt quite the opposite, for example the dietician commented:

> I think our MCN, has been very much Scottish Exec driven, so all their priorities have been things like the retinal screening… and all the things that have come from the top down… it's not, to be honest, been particularly supportive of anything that's been needed at a local level.

Clinicians based in the secondary care clinic went on to suggest that the MCN had failed to address local needs because it had not involved secondary care. The secondary care clinicians had previously been very active in training primary care professionals and promoting diabetes care across the Health Board. However, with the advent of the MCN they felt that these efforts had been undermined by an externally driven force which did not include them sufficiently in discussions of care delivery. Consultations carried out by the MCN seemed to have involved primary care professionals more than previously, but the secondary care professionals felt that they had been excluded from key decisions. For example, I was told that the MCN manager had consulted primary care clinicians about the introduction of a new diabetes patient education program, but secondary care professionals said that they resented that they had not been involved in this decision. Like at Silvenea, professionals from one sector were more positive about the MCN than the other, suggesting that the MCN was being perceived in terms of traditional boundaries rather than overcoming them.

In all three cases the MCN was interpreted in relation to existing tensions across primary and secondary care boundaries rather than overcoming these. It was viewed by clinicians from their situated perspectives, both organisationally and in relation to the historical organisation of care in the area. Health policies were interpreted in terms of existing relationships across professional boundaries but also reinforced and informed these relationships. This ongoing interaction between policies and professional identity could also be seen to be occurring in the interpretations 'external' professionals placed on the actions of their colleagues in general practice following the implementation of the financially incentivised clinical targets of QOF.

QOF incentives from the perspective of professionals based outwith the general practices

Allied health professionals and those based in secondary care had two main comments to make about QOF. Firstly it was generally perceived as the cause of an increased rate of referrals. For example, Alan, the podiatrist for Silvenea, commented:

> Certainly we see far more diabetics in the last three or four years… Cos, [after the nGMS contract] every surgery started doing their own individual diabetic assessment clinic. I believe that they were actually being financially rewarded… and it made a huge input to the podiatry workload.

Secondly, allied health professionals and DSNs commented on whether they thought the QOF had improved patient care. The DSN at Silvenea said that, whilst she had concerns over whether patients were receiving appropriate treatment in primary care in general, she thought the nGMS contract would pull primary care up to standard because they had to reach the targets. However, the dietician at Corryhabbie, and the DSN at Strathfinella both expressed concerns that, in general, primary care were inappropriately referring patients to start using insulin at an earlier stage of their disease. Jane, the dietician at Corryhabbie, commented:

> I think because of all these points, they're too busy ticking boxes and actually forget about the person as a whole... And there's a couple of practices that really are bad for it… Corryhabbie is pretty bad.

Sarah, the DSN for Strathfinella presented a similar view:

> Some practices refer very early, as soon as the HbA_{1c}'s off target… it's all about money. Everything the GP does is about money. I think altruism is well gone… it was always going to happen that if you offer people money for doing something, they will do it. But without regard to, is that necessarily the best thing and are they then doing it for the right reasons... does that mean then that patient's going to get care because it'll make [QOF] points, or is it better that, for you as a person, we do [something else]…OK, it may well be positive for a number of people but, without doubt, there are a number of people for whom it won't be positive… money just drives everything. I think it's really sad.

Allied and secondary care clinicians' interpretations of their primary care colleagues' actions were informed by their knowledge of QOF's financial incentives. The QOF informed a sense of suspicion that general practices were acting out of pure financial motivation rather than out of concern for their patients. This undermined a basis of trust between healthcare sectors and increased what Sarah described as the "chasm" between them. However, it is also worth noting in the above quote that Sarah is referring to a stereotyped perception of GPs in general, whilst Jane specifically names Corryhabbie as one of the practices whom she thinks is trying to push for better blood glucose control without taking note of patients' wishes and lifestyle.

As I will now go on to discuss, this interaction between policy, identity and trust across professional boundaries also influenced professionals' preferences for the source of the clinical evidence they used. In particular, the relationships across professional boundaries appeared to influence professionals' claims that they used the diabetes MCN clinical guidelines.

Inter-professional relationships and evidence for clinical practice: choosing guidelines

As mentioned above, each diabetes MCN has produced local clinical guidelines in order to "facilitate the development of a common standard of care… and provide guidance on access to the various support services that are available" (MCN for Health Board B website). Prior to the publication of the local MCN guidelines there was already an expectation that clinical care for diabetes should follow the national SIGN guidelines for diabetes, SIGN 55 (Scottish Intercollegiate Guidelines Network, 2001). However, most clinicians I interviewed claimed to prefer to use the MCN guidelines rather than those published by SIGN.

At each of the three practices I was told that a paper copy of the SIGN diabetes guideline had been received through the post, but at none of the practices did these paper documents seem to be in regular use. For example, at Strathfinella the practice manager

told me that she did not tend to pass the paper copies directly to the doctors because they "said that they don't always find them useful", but she hypothesised that the GPs would look for them online if they needed them for anything. Similarly, at Corryhabbie Dr Andrews, told me that she had looked in their 'library' for the SIGN diabetes guidelines before I arrived and had not been able to find a copy.

Susie, Silvenea's district nurse, was particularly interested in caring for diabetes (partly because she had the condition herself) and took quite a different view of the SIGN guideline. She was the only professional across all three practices who claimed to refer directly to the SIGN guidelines (rather than the MCN guidelines) in her everyday work:

> If there's a treatment decision to be made about a patient, I would be looking at [SIGN guidelines] to see where I should be going or where I'm checking up on somebody's bloods, when was their HbA_{1c} last done, how often should it be done? It's in the SIGN guidelines.

Other health professionals I interviewed at Strathfinella and Corryhabbie did not claim to directly refer to the SIGN guidelines, but assumed that the local MCN guidelines were based on SIGN, which were unquestioned in their authority by all but Dr. Harrison at Silvenea. For example Dr. Shore at Corryhabbie commented:

> I'm not aware of the differences if there are differences so I think if we're following the local thing, it's going to be pretty close to the SIGN ones. So if I'm needing guidance, I'll haul up the local one.

SIGN guidelines were presented as a trustworthy source of evidence for clinical practice with nearly every clinician claiming that their practice adhered to the SIGN guidelines through using the local guideline. Even Dr Harrison, who I will show rejected the notion of guidelines in general, claimed that he knew what the SIGN guidelines said.

So, given the credence of SIGN, why did health professionals continue to prefer to use the local, MCN guidelines rather than referring directly to SIGN? In order to answer this question I will first compare the SIGN and MCN guideline documents themselves before returning to analyse the various professionals' perceptions of these.

Differences between SIGN and MCN guidelines

At the time of my fieldwork health professionals in each of the three case studies claimed to use MCN guidelines from different Health Boards. These local MCN guidelines did not differ from each other or from SIGN in areas where substantially sized clinical trials have suggested specific biomedically defined targets and clinical practices. For example, the diagnostic criteria for diabetes in the guidelines were drawn from the World Health Organisation, and did not differ, nor did clinical targets such as those for blood glucose control (HbA_{1c} of around 7%), blood pressure control (<140/80 mm Hg), or pharmaceutical treatment recommendations. However, in some areas the SIGN 55 guideline stated that the evidence which they have collated is equivocal, as, for example, is the case for self monitoring of blood glucose in type 2 diabetes. Also whilst the SIGN guideline suggested what clinical care should be provided it did not give advice on where particular aspects of care should be provided or by whom (Scottish Intercollegiate Guidelines Network, 2001).

The local MCN guidelines filled in the areas of the SIGN guidelines which remained ambivalent due a lack of evidence by drawing on a consensus of MCN members and guidance from other sources; for example, Diabetes UK. The MCN guidelines also added an extra layer of detail which included: where care should be provided, by whom and which blood glucose monitoring equipment should be provided to patients within that Health Board. The example of dietary advice for patients with type 2 diabetes as outlined in the guidelines of the three MCNs illustrates this point.

The SIGN guideline stated that healthy eating is of "fundamental importance" for all people with diabetes. It also stated that diabetes patients' readiness to change dietary behaviour should be assessed and that clinical interventions aimed at dietary change are more likely to be successful if a "psychological approach based on a theoretical model is included" (Scottish Intercollegiate Guidelines Network, 2001). Who should provide dietary advice and the details of what this should contain were not specifically stated in the guideline itself. In contrast, each of the local MCN guidelines provided a checklist of

what dietary advice should be given at diagnosis, when patients might be referred to a dietician, and where a dietician was located. They also indicated what literature, either produced by local dietetic departments or by Diabetes UK, might be referred to by the clinician and/or given to patients. All three of the MCN guidelines also drew on the Diabetes UK recommendations in stating that a dietetic consultation should be provided within four weeks of diagnosis. The different MCN guidelines did not vary greatly in this advice, but the advice was specific to the organisation of care within each Health Board, reflecting the availability and location of allied health professionals and secondary care. However, as I will now go on to discuss, professionals' accounts of using the guidelines suggested that the more specific advice of MCN guidelines only partially explains their preference for them over SIGN guidelines. The local consensus involved in creating MCN guidelines also coloured professionals' perceptions and claims to use them.

Consensus and trust in MCN guidelines

MCNs include representatives from both primary and secondary care and allied health professionals based both within the community and in secondary care. Hence, the guidelines they have produced are a product of collaboration and consensus across these sectors. This collaboration in itself was viewed as a reason to use the local guidelines, as is suggested by the following quote from Dr. Scott at Strathfinella:

> I tend not to use the SIGN guidelines for diabetes because we have got [MCN] guidelines which are based on SIGN guidelines… I like the MCN guidelines, I understand them, they're produced by local consultants in conjunction with primary care here, so I'll use them.

Health professionals from both Corryhabbie and Strathfinella emphasised that there were two reasons for using the MCN guidelines. Firstly, they were assumed to be based on the SIGN guideline, and secondly they were created through a consensus of local professionals situated both within their own and other professional fields, who were either known to them personally or through the institutions they represented. This meant

that at Strathfinella, where a relationship of collaboration and trust between secondary and primary care was already established, the guidelines were also trusted and preferred to those created by the unknown professionals of SIGN. Whilst trust in SIGN involved instrumental expectations of unknown others, trust in the MCN guidelines included both instrumental and axiological expectations of known professionals or those assumed to have shared interests. Drawing on Sztompka's theory of trust (1999), I would argue that because trust in MCN guidelines draws on multiple layers of trust including people socially closer to the trustor, they engender a stronger 'commitment'.

The local guidelines were also preferred because of their basis in local professional consensus at Corryhabbie. For example, Patricia, the DSN, commented:

> We use the [MCN] guidelines which everyone participated in writing and which are all evidence based and based on the national guidelines.

However, as the local guidelines were a product of a collaboration of local clinicians, their use was also placed within the context of the ongoing inter-professional relationships presented above. This is exemplified by the way in which Dr. Andrews presented the importance placed on the use of the MCN guidelines at Corryhabbie:

> We are quite firm about sticking to the guidelines. Because I think if you use the local [MCN] guidelines, these are developed with primary and secondary care and also you can't be challenged for giving out prescriptions unnecessarily or spending money inappropriately… But I don't think its just watching your back, I think it's about good care… you shouldn't do things on gut instinct. You should do it on what somebody has spent time developing and reading and presumably that's based on the SIGN guidelines as well.

Dr. Andrews went on to explain that, even if published clinical trials had indicated that a particular drug should or should not be used, the practice would wait for the guidelines to be changed in confirmation of this before changing their practice. The local guidelines were expected to inform "good care" because Dr. Andrews 'presumes' that they are based on SIGN, and have been created through "someone" taking time and effort over their development. Dr Andrews is expressing a form of instrumental expectation, a trust

that MCN guidelines are the product of "someone" following a thorough and recognised procedure of collating scientific evidence.

However, interestingly, Dr Andrews also highlights that because the MCN guidelines represent a collaboration, an agreement between primary and secondary care, they can be used as a defence against accusations of inappropriate practice. They play a role in "watching your back", but from whom? Dr. Andrew's reference to money suggests that the agreement the guidelines represent mean that the practice will not be criticised by the Health Board for over-spending. However, given the tensions already discussed between primary and secondary care at Corryhabbie, it is possible that using the guidelines agreed between these two sectors is a way of trying to avoid criticism from secondary care. Certainly as our interview progressed it became clear that Dr. Andrews' perception of the MCN guidelines was coloured by this ongoing inter-professional relationship, and the perception that the MCN acted primarily in the interests of secondary care:

> I mean it's interesting, the hospital with type twos used to bring people back every six months or a year, but they actually tell us we're supposed to see them every three months. Well that's just not feasible.
> **The hospital tells you?**
> The hospital says - the guidelines says everybody with type two should be seen every three months. And you think no, no, that's not going to happen. So you were asking about guidelines, well we tend to ignore that one.

On the one hand MCN guidelines were perceived as trustworthy and a tool for promoting collaboration because they were based on both SIGN and local consensus. On the other hand, the guidelines themselves were interpreted through existing inter-professional relationships. When guidelines were perceived to be biased, suggesting one practice for primary care, when it was already known secondary care did something different, the consensus on which the guidelines were based was undermined. The guideline was perceived as invalid and was 'ignored'. Trust in the guidelines was tied to trust in the health professional colleagues involved in their writing and imbued with, or lacking the same axiological trust as those colleagues.

However, guidelines were not the sole source of evidence drawn on by the professionals to inform clinical decisions. In the next section I will go on to argue that the encapsulation of guidelines in the form of QOF targets was perceived to have a much more direct impact on daily care. In addition, various clinicians said they also referred to the Diabetes UK website and drew on research published in professional journals. Indeed, at Silvenea Dr. Harrison's attitude towards clinical guidelines in general was that they were an inadequate source of evidence for his clinical practice:

> The guidelines have got a very useful place in the practice and that's the bin… they change all the time and they're not the guidelines you want… If I went to [a clinical presentation] and it's well presented and it was obvious that it was non drug sponsored and if you'd figured out the risk and the paper was peer reviewed and, you looked up some of the references, which I always do, check to see if any of my pals were involved in it. Then I would change my practice tomorrow. I wouldn't wait for the guideline to come out to tell me about it… I think SIGN is a particularly useless organisation; their guidelines on the whole are out of date because any guideline that's more than a year old is out of date…. my diabetic care was changed by going to a meeting and having some evidence explained to me very clearly that, that was a very important landmark study [UKPDS] and it just seemed to take ages for this to disseminate out.

Dr Harrison was aware of the SIGN guidelines and had been involved in the early stages of developing the local MCN guidelines. However, guidelines quickly went out of date and never exactly apply to the case of each individual patient. In direct contrast to the approach at Corryhabbie, he would also change his practice immediately, having critically assessed the research evidence for himself, rather than waiting for a guideline. Dr Harrison's trust is directed towards the presentation of evidence and the people presenting that evidence rather than it being brought together by SIGN. His trust involved a combination of instrumental expectations of scientific method, and axiological expectations of "his pals", but these varieties of expectation were directed at a different target to that of the professionals' trust in the other two case studies.

Dr. Harrison went on to point out that, within the paradigm of evidence-based medicine, doctors are being trained both "to follow guidelines but… also to read papers more

critically" which he saw as two incongruent approaches. He positions himself as following the more critical approach to evidence which, as has been discussed by Timmermans and Berg (2003), maintains the need for a wide range of evidence in making clinical decisions. Whilst claiming not to use guidelines, Dr. Harrison presents himself as a critically engaged and exercising his professional judgement and clinical autonomy.

This maintenance of clinical autonomy has been considered core to professional identity (Abbott, 1988; Harrison and Ahmad, 2000) and has been discussed elsewhere as a key influence on the implementation of guidelines (Armstrong, 2002; Checkland, 2004). In the next section I will discuss the difference between guidelines and the QOF targets from the perspective of the clinicians across the case studies. I will show that the question of clinical autonomy in relation to these policy instruments was an important factor influencing which particular clinicians were involved in delivering care within each general practice.

QOF and the organisation of care within the practice

In the previous chapter I claimed that the particular organisation of the diabetes clinic in each practice could be partly explained by the 'ethos' of the practice as a whole. In this section I will further my explanation of the differing organisations of the practices' diabetes clinics by considering why certain clinicians were more involved in diabetes care than others at each practice. At Silvenea, Dr. Harrison, the fulltime GP, carried out all diabetes review appointments. At Corryhabbie, Vicki, a peripatetic nurse, ran a diabetes clinic two days a week and consulted once a week with Dr. Andrews if she had any difficulties. At Strathfinella, Erica, the practice nurse, carried out diabetes review appointments with patients and later discussed results and made clinical decisions in conjunction with one of the GP leads. Patients might then be invited to an appointment with one of these GPs if any changes to their disease management were deemed

clinically necessary. In this section I will argue that these differences can be explained in terms of whether diabetes care was perceived as routine and protocol-driven.

'Tick box medicine' and the role of the computer

A key difference clinicians at all three practices perceived between guidelines and QOF targets were the varying degrees of flexibility they allowed for the exercise of clinical autonomy. Whilst professionals might continue to exercise their discretion with guidelines, this was not the case with QOF targets, as Dr. Scott at Strathfinella observed:

> In some ways I quite like guidelines, I don't like tick box medicine but I like that structure to work within and then you can deviate from it, as you feel appropriate and what I find with the tick boxes [QOF targets] is that they're too restrictive, you've gotta hit the targets and I sometimes think that's not appropriate.

As in previous research by Gabbay and le May (2004), I found that most of the clinicians considered guidelines an aide memoire. Guidelines were drawn on selectively as a source of information when a clinician could not remember an exact figure or measurement. In contrast, QOF targets were perceived as more "restrictive".

With no loss of income, clinicians can deviate from the QOF by 'exception reporting' patients they judge a particular target to be inappropriate for, but QOF was still perceived as highly directive. This was perhaps because, in contrast to deviating from a guideline, exception reporting requires a written explanation at the time of the decision and may be challenged by colleagues. Through the daily implementation of QOF every variation in clinical judgement made in every consultation, appropriate or not, becomes more explicit. This in itself may lead clinicians to feel that they are more constrained.

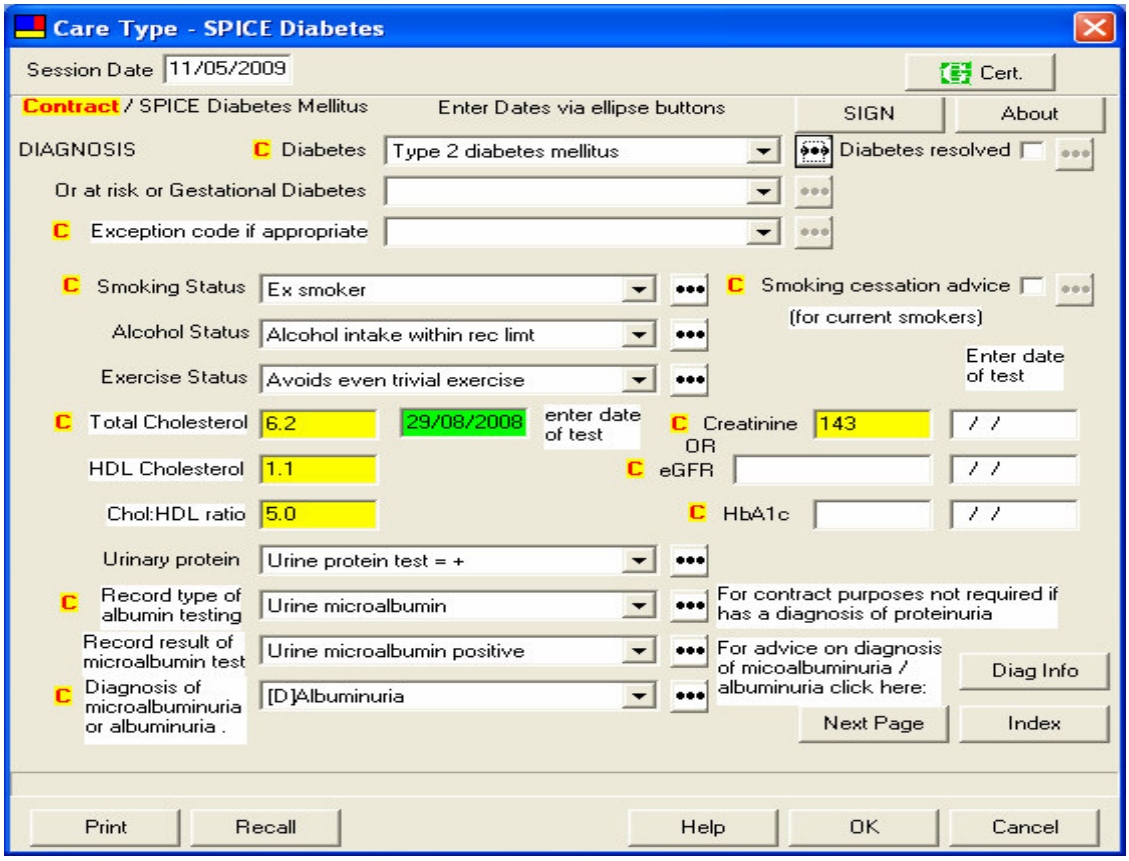
The way in which the QOF targets enter the consultation may have also added to the perception of QOF targets as more directing than guidelines. In my interview with Dr Andrews from Corryhabbie, I asked her whether she referred to clinical guidelines in her daily practice:

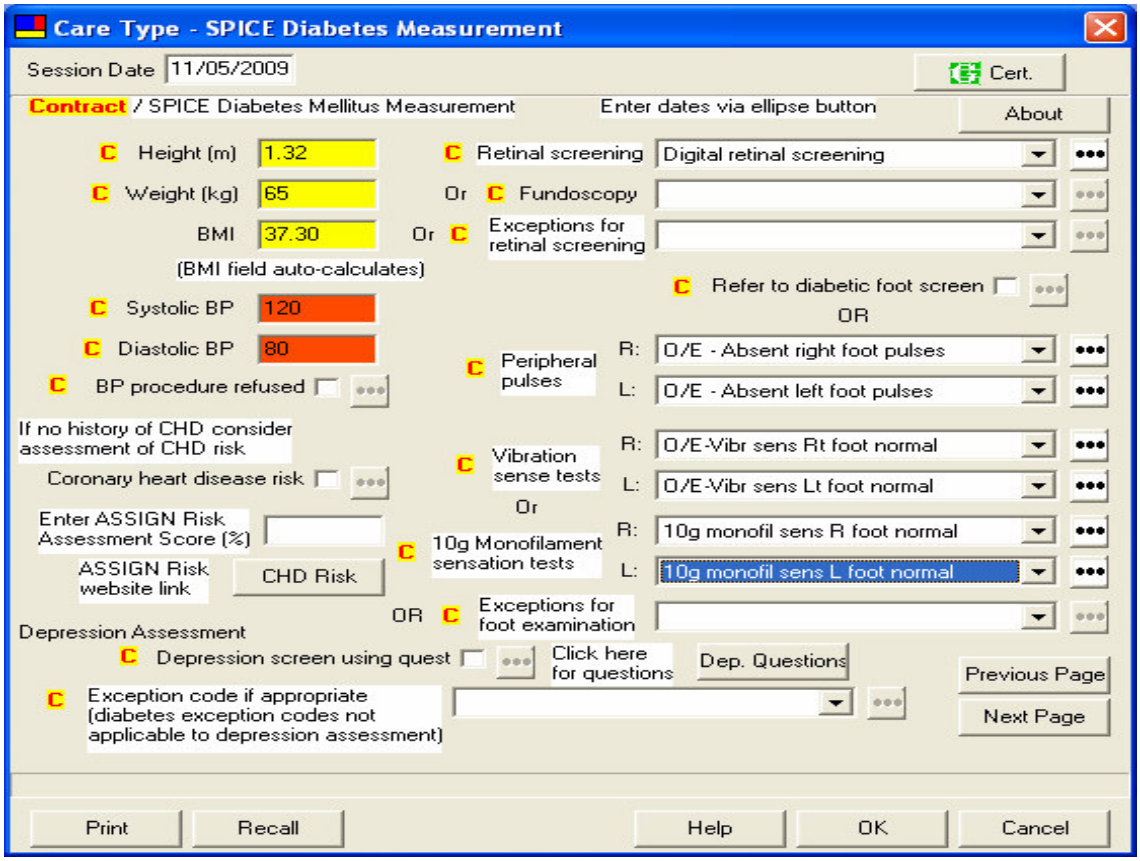
> I think it depends on how they're structured because at the end of the day in order to get the information that you require when you see a patient, you have to go through what's on the computer and that's based on the guidelines.

Clinical guidelines as embedded in QOF targets are more immediately present in every consultation. In contrast to earlier guideline documents which had been sought out by the clinician as and when they considered it necessary, the QOF targets are always present and the computer system draws the clinician's attention to them. To further illustrate this point, below are two examples of computer screens which were used for maintaining patient records and to collect data for the QOF targets.

The first two screens are taken from GPASS, the clinical records system which was used by two out of three of the practices involved in my research, and by 80% of practices in Scotland (GPASS and NHS Scotland, 2005). The red "C" next to some of the data to be recorded indicates which aspects need to be completed to meet the QOF targets of the nGMS contract.

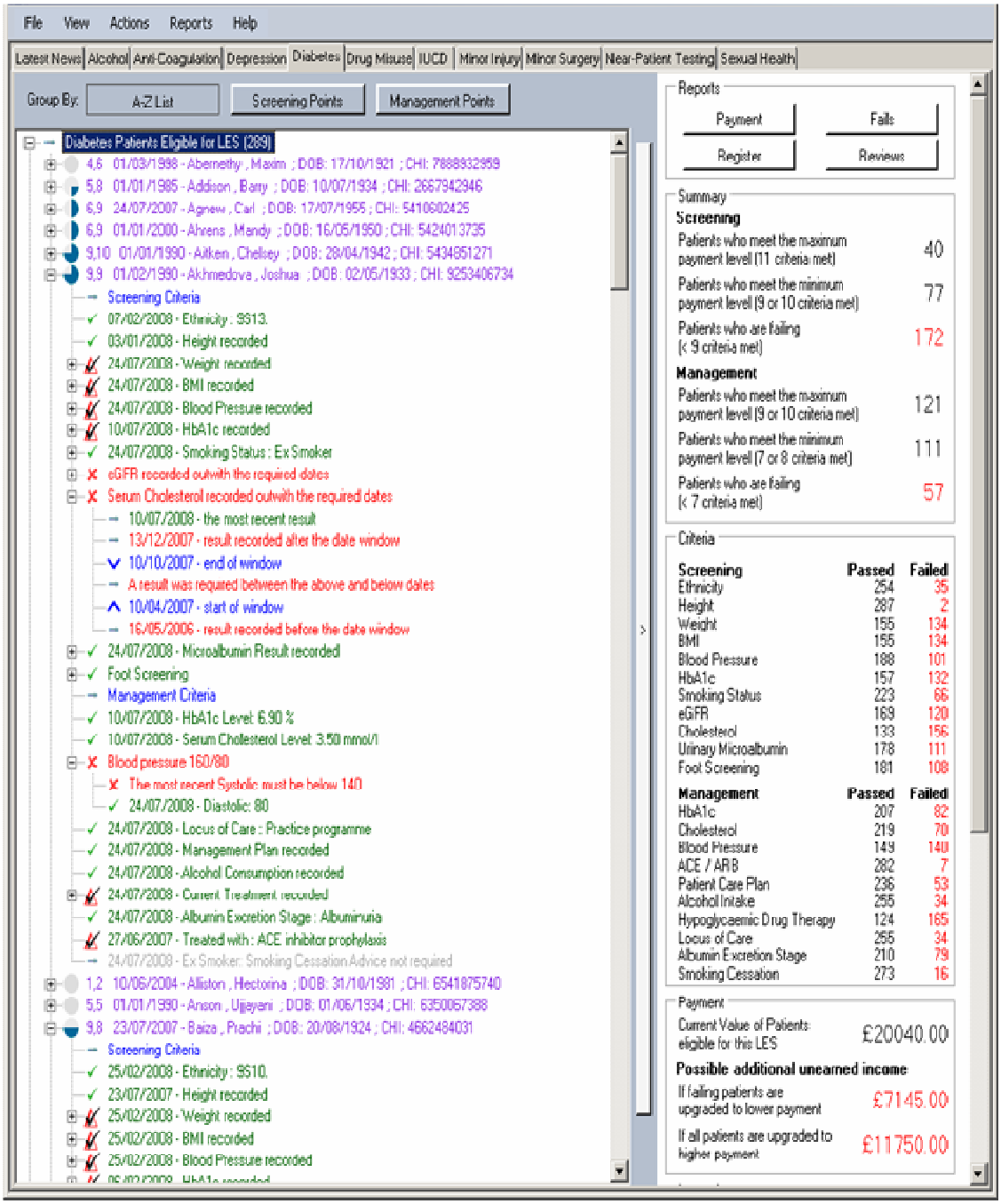
GPASS SPICE Screen for Diabetes (Data is fictional)





From the GPASS screens above it is clear to see exactly what tasks the clinician is expected to complete when the patient attends for their diabetes review, guiding the clinician's actions. The next screen is taken from EScro, a program used at Strathfinella for the implementation of the locally enhanced service (LES) for diabetes. The LES is a part of the nGMS contract through which Health Boards can employ practices to provide additional services. In this case it is being used as a further incentive for diabetes care in addition to the QOF and involves the same targets. The EScro screen meets both the needs of the LES and records the necessary data for QOF by automatically populating the GPASS screen already shown above.

EScro screen (From a training version, fictional data)



Again one can see how the computer programme guides the clinician through the tasks to meet the clinical targets of the QOF and LES. It also very obviously links these to the

financial rewards outlined in the right hand column, perhaps in order to motivate the clinician's clinical practice. As the quotes from Dr. Scott and Dr. Andrews above illustrate, this is viewed as much more directive than the use of clinical guidelines. From their perspective, QOF, implemented through the computer system, can be understood to represent an example of the co-option of evidence based medicine by the state, threatening the profession's clinical autonomy (Timmermans and Berg, 2003). Moreover, the standard format of the computer programmes shapes what clinical information is recorded about a patient, prioritising certain forms of knowledge about the patient whilst silencing others. The aspects which are silenced, or at least, not recorded in the screens above, are those most central to the patient's subjective experience of illness within the context of their life-world.

As recognised elsewhere (McDonald et al., 2007), I found doctors and nurses at Silvenea and Strathfinella were anxious about the impact of the computer-based implementation of QOF on the patient-professional interaction in consultations. For example, when I asked Dr Crawford at Silvenea to outline what she felt were the pros and cons of the contract, she commented:

> With the new contract the very best I could say about it is that it's giving me reminders to check that I've done certain tasks for certain groups of patients… it's undermining care in many subtle ways, which are quite difficult to quantify… it's changed the consultation with an individual patient. So if somebody comes in now, the doctor's attention is very much on the computer screen, and we're very much focused around, have we done this task and this task… I would much rather practice a style of medicine which starts with the patients being the main focus, not the computer screen.

Dr. Crawford was particularly cynical about the impact of the computer on her consultations, but was not alone. Both doctors and nurses from Silvenea and Strathfinella were concerned that the computer had the potential to distract their attention away from the individual situation of the patient with the need to meet targets and collect QOF points. Clinicians at both of these practices had taken steps to "put a circle around" (Dr. Crawford, Silvenea) taking the QOF measurements. For example at

Silvenea, this was Dr. Crawford's explanation for organising diabetes care into a clinic. Although this meant that the computer was still present in the diabetes review, the review would not interfere with everyday general practice patient-GP consultations.

At Strathfinella, as I described in chapter four, a conscious separation between addressing QOF targets for diabetes and the interaction with the patients had been made. Erica, the practice nurse, consulted with the patient and then a few weeks later, she and Dr. Scott (or Dr. Gion) would fill in the "tick boxes" for QOF. During my observation of one of these meetings, Dr. Scott explained that this separation enabled them to meet both the requirements of the "contract" and facilitate "quality", which she commented were not always the same thing. In this way, Dr. Scott believed that they had solved the problem of QOF targets interfering with the patient-professional interactions in both Erica's consultation and her own:

> It's much easier for me because I can now separate seeing the patient from the tick boxes and… those patients where I do feel I need to see them… to discuss complications or whatever, actually I'm just speaking to the patient, I can leave the tick boxes aside because we've done that separately.

This particular approach to implementing aspects of QOF was congruent with the professional's emphasis on "holistic care" achieved through separating communication with patients in the consultation from the biomedical targets of QOF and then recombining these concerns in the absence of the patient, as I outlined in the previous chapter.

In contrast to Strathfinella and Silvenea, at Corryhabbie, Vicki, the diabetes nurse, rejected the argument that the computer impeded patient-professional communication. She was enthusiastic to show me how she used the Vision computer system to assist patient-professional communication. During our interview Vicki opened up the computer-based notes of a fictional patient and explained how she would use the computer in a consultation setting:

> This is the template for diabetes… I'll often say to the patient, come in so we have a wee look at this… and I talk them through it so they can see what's happening... I'm saying, look at your HbA_{1c}. Now, let's see where we're going with that and… what therapy are you on? Oh, you're not on anything for your diabetes... you can go way back to 2004, and you can see their deterioration in control and what's happening, and I will print it out for some of the patients, because… there's a lot of them are quite hung up on this and they just love to see this… and I'll say, now here's your target, so I use the computer as an educational tool. Okay, I'm storing all the information… but they don't see it as that, they see it as their information that they can look at… it's good from that point of view. That's how I use it.

Vicki's approach to using the computer system involved educating patients in the biomedical understanding of their condition. Her approach, understood within the context of the ethos of Corryhabbie as presented in chapter four, suggests that she did not place the same emphasis on the patients' psychosocial context as professionals at the other practices. So, the computer was not perceived as a hindrance to communication but a facilitator of patient education.

In addition to the varying approaches of bracketing out the influence of the QOF from the consultation, or adapting the recording of data into an educational tool, the QOF targets themselves were critiqued by doctors and nurses.

Questioning targets

As in previous studies of the QOF (McDonald et al., 2007) I found that, whilst the clinical targets were experienced as restrictive, most were also generally considered to improve clinical outcomes. For example, Dr. Shore at Corryhabbie commented:

> One of the QOF points is for HbA_{1c}, which measures diabetic care, and you get some extra points if you get somebody down below a certain level... That does drive the behaviour of what we do here… I think there's been a lot of positive stuff there for sort of outcomes of patient wellbeing there.

The clinical management of patients was perceived to be improved at Corryhabbie through the QOF indicators. Interestingly, HbA_{1c} is presented as *the* measure of "diabetic care". Dr Shore also conflates improvements in the biomedical marker with

patients' "wellbeing", reflecting the biomedical focus of Corryhabbie and the significant weight which professionals at all three practices placed on the HbA_{1c} measure. Dr Shore went on to comment positively on the increased structure and funding brought to the practice by the implementation of the nGMS contract, and how he felt this had enabled the practice to provide better care. Similarly, Dr. Scott at Strathfinella described how her attitude towards the nGMS contract and clinical targets had changed:

> I voted against [the contract] but nevertheless there were bits that I will actually say… this does appear to have been clinically motivated and, some of these are good goals. They are sensible to strive for… [for example] some of the stuff that came from UKPDS studies.

Most of the clinical targets incorporated into QOF were considered to further good care and supported greater attention to trying to achieve the goals which were perceived to have a 'good' evidence base, such as the UKPDS studies. The clinical targets were not accepted at face value but were judged against the professional's existing knowledge of best clinical practice. In addition, the increased level of external accountability the QOF had brought was also welcomed by some GPs, particularly Dr. Macleod at Strathfinella:

> I think there's a lot more evidence based care going on, which is good because people are more accountable and I think in the past a lot of GPs weren't that accountable, they did it their way without really paying heed to evidence, [or] cost effectiveness of therapies… there were far too many characters.. [and] I'm not sure they were practicing particularly good medicine. [But]… it's still an art this job… it's not a science, in that not everything's gonna be evidence based.

QOF has not reached "the elusive fusion between scientific knowledge and clinical practice" which would "turn the art of medicine into a science" (Timmermans and Berg, 2003,87). QOF targets do not cover much of everyday general practice and, by emphasising the continued "art" of medicine, Dr. Macleod also defends its independence from external direction. However, he simultaneously approves of the 'evidence based', 'scientific' approach of QOF. His attitude towards QOF sits in line with the overall ethos of Strathfinella moving away from "old-fashioned general practice" whilst retaining a patient-centred approach.

GPs and nurses at all three practices also criticised QOF on various fronts. For example, they complained that by including some clinical areas and excluding others, QOF potentially directed the clinician's attention away from other significant disease areas in the population. In addition, GPs at Silvenea and Corryhabbie directly questioned some of the evidence supporting QOF targets. As Dr Shore commented, they thought that:

> The first generation of indicators and targets probably were quite well evidence based. The lot they brought in last year [2006] rather less so.

Placing incentives on apparently poorly evidenced practices lay in particular tension with ideals of providing patient-centred care. For example, Dr. Harrison at Silvenea questioned the appropriateness of some clinical procedures required by the QOF:

> There are aspects of the contract that we've done even though I would disagree with them and that includes some aspects of the diabetic care. For instance, checking out cholesterol annually is tantamount to assault I feel… If you were taking their blood just for the cholesterol but not for anything else, then it's not gonna influence clinical management and it is an assault on somebody's person… you're putting a needle into them and if you're doing that for no good reason, then that's almost an assault.

Both Dr. Harrison and Dr. Shore had come to their own conclusions about the evidence underpinning aspects of the contract and Dr. Harrison in particular expressed concern about the ethical implications of this in terms of providing care. The approach to 'holistic' care at each practice seemed to mediate the implementation of those QOF targets perceived to be based on less 'evidence', and which appeared to infringe on general practice ideals of patient-centred care. This is particularly well illustrated by the ways in which the three practices approached the depression indicators in the QOF.

Depression screening questions

In 2006 two QOF targets were introduced to reward practices for screening patients with diabetes or coronary heart disease (CHD) for depression. These require the practice to ask all patients with diabetes (or CHD) two standardised questions and, if they were

thought to be depressed, to provide an assessment using a tool validated for use in primary care.

At Silvenea, Dr. Harrison and his partner had decided to opt out of the depression indicators in the contract. Dr. Harrison explained to me that he thought that the new depression indicator questions and assessment tool, were "obviously not only non-evidence based but potentially harmful". He thought that to ask questions in the format laid out by the contract would be distressing for patients and also that he would already be aware of depression in his patients given his regular contact and personal knowledge of them. He viewed the depression questions as contradictory to the particular approach to holistic care at Silvenea. Interestingly, the threat the depression indicators posed to the patient-professional relationship seemed more of a concern to Dr Harrison than his view of cholesterol measurements as "assault".

Choosing not to take part in the depression indicators at Silvenea meant that the practice missed out on 33 points out of a possible total of 1,000 in the QOF. From an analysis of the publicly available QOF data relating to Silvenea, I have calculated that each point was worth approximately £25 to Silvenea (ISD Scotland, 2007). Hence, by opting out of the depression indicators, Silvenea lost £825 out of a possible QOF total £24,900. This is a small amount of money in relation to the total available. The GPs presented themselves as having taken the moral stance, but it had not cost them dearly to do so. Also it was not clear why they had not exercised the same discretion with other areas of the contract Dr Harrison disagreed with, except that it would have incurred more loss of income. In explaining his stance, Dr. Harrison hypothesised how other practices might approach the depression questions:

> How less personal can you get than receiving a phone call… saying over the course of the past month, have you had feelings of hopelessness? As practices realise they haven't done DEP one and two, they're using telephone consultations, using strangers… I mean, how more impersonal can you get than that?

As Dr. Harrison supposes, practices did reach the end of the financial year and realise that they had not completed the depression indicators; Corryhabbie was one of these practices. Dr. Andrews explained that they had completed the depression targets by sending out letters with the contract's set questions and asking patients to contact the practice if they felt they needed to:

> We'd got towards the end of the year and realised we hadn't asked a fairly significant percentage of our patients… nurses had difficulty in asking the questions… because if you get the answers that need [community psychology] support, that's actually quite a big problem [because the service had been withdrawn] …But the amazing thing was… we just sent out letters… and we had very few responses… Phew… it is difficult. How can you ask that question without having the resources?

I was told by Dr. Shore that asking the depression screening questions was a task which was to be undertaken in the nurse-led clinics for diabetes and CHD. The GPs did not ask these questions; they were viewed as part of the protocol-driven care of the QOF, and hence, as I will go onto discuss further, the remit of the nursing staff. In this way the GPs also excused themselves from responsibility for not having asked the questions. Once depression was suspected Dr. Andrews also implied that depression is something which should be managed by a community psychology team rather than by the GPs. This reflects the highly defined divisions of labour at Corryhabbie, but due to a lack of resources regionally, they had no access to community psychology services. Despite this concern they still sent out the depression letters and were relieved to find they had few responses. Sending out letters meant that the onus to make an appointment about their depression is placed on the patient. This approach also reflects the health professionals' expectations of the patient's role as a consumer which I described in chapter four. In a sense this gives patients' choice, but perhaps also reflects a lack of care.

The approach to the depression indicators again differed at Strathfinella, where I asked Erica how the practice had approached the depression questions:

> Well, when I see the patients, it's one of the first questions on my list on the EScro screen. [I ask] "How are you doing at the moment ?", and it depends,

> if I've seen them more frequently I won't ask them but if I've not seen them say for six months, nine months I'll say, you know, "have you been feeling down at all of late?"… that's generally my term… and so the conversation then sort of opens up… it's hugely important question to ask but [the screen is] a real prompter to remember to ask.

Erica did not necessarily use the QOF depression questions as laid out in the nGMS contract, which in a sense means that she was not meeting the QOF target, but she did address the topic. The demands of QOF were incorporated into a more personal and contextualised approach. As already discussed, in Erica's consultation the focus was on communication with the patient rather than 'ticking the boxes'. However, the tasks within that consultation were still partly directed by the QOF targets acting as 'reminders'.

Whilst the QOF targets were standardising the topics covered by the practices (with the possible exception of Silvenea's opting-out of the depression indicators), the way in which the targets were actually met continued to show variation. At each of the three practices the approach to implementing the QOF depression indicator was mediated by the approach to personal and holistic care adopted at the practice as a whole.

Armstrong (2002) has suggested that appeals to patient-centred care enable health professionals to continue to exercise professional autonomy in the application of clinical guidelines. My data suggests that individual GPs in particular felt that their clinical autonomy was more restricted by the QOF than it had previously been by other forms of clinical guidelines. However, particular organisational approaches of "putting a circle" around or opting out of certain areas of the QOF, were justified in terms of patient-centred care. The use of patient-centred care as a discourse to justify variation in practice had shifted from the ins and outs of decisions in individual consultations to justifying care organisation. I will now go on to show that part of "putting a circle around" QOF involved delegating diabetes care to nursing staff in the practices where it was viewed as routine and protocol driven.

Nurses follow protocols, doctors exercise clinical judgement

As shown above, QOF was viewed as much more prescriptive and task orientated than guidelines. It was viewed as a "protocol" rather than a "guideline" and the use of protocols rather than guidelines was considered a core difference between nursing and medicine by GPs at all three surgeries. For example, Dr Macleod at Strathfinella commented:

> [QOF targets have] improved our care because it focused us and because the care has also gone over to nurse led areas, nurses are very good at working with protocols. So if you've got to hit certain buttons… they do it very well.

Because diabetes care followed protocols such as QOF it could be passed on to nurses, and this had improved the clinical outcomes of disease management. Dr Shore at Corryhabbie also explained why he thought it was appropriate to have nurse-led clinics for diabetes:

> I think an awful lot of it doesn't need doctor level input anyway. It's more appropriately done by a nurse and it's quite clear that nurses are much better at following protocols than doctors… I think GPs are used to kind of having variety in their work… they don't know what's coming in next and it's stimulating and interesting and exciting and sitting in a clinic with yet another of the same thing coming in with the same questions to be asked, the same boxes to be ticked, it just starts to feel kind of humdrum and routine.

However, in contrast to Strathfinella and Corryhabbie where, because it was viewed as routine, it was considered appropriate for nurses to carry out diabetes care, at Silvenea Dr. Harrison completely rejected the notion of nurse-led clinics for diabetes. Despite the fact that the practice nurse at Silvenea had completed further training in diabetes care and ran a diabetes clinic at another practice, Dr Harrison thought that diabetes care should remain part of the GP's work:

> I think the difference is that you train a nurse to do something whereas you educate a doctor… Why you have nurse led clinics is that nurses follow protocols very well and ultimately what it comes down to is whether you follow the protocol or whether you're using your clinical judgment and guidelines and it's the difference between protocols and guidelines… a good

> doctor should have more experience in other fields, and pick up other things [which a nurse may miss].

Dr. Harrison agreed with Drs Shore and Macleod that nurses were more protocol and task orientated; however, for this very reason he thought that it was inappropriate for a nurse to be the sole clinician running a diabetes clinic. Nurses might miss clinically relevant problems which were not in the protocol. However, Dr Harrison might also be defending the importance of his own role as a rural practitioner, given the general belief he expressed that his practice would no longer continue to exist after his retirement. He felt that the roles of small, remote and rural general practitioners were being increasingly covered by satellite-surgeries and community nurses.

Although the professional identities of doctors and nurses in terms of the work they do was the same across all three practices, the implications of this for the organisation of diabetes care were quite different. This was because diabetes care was not considered routine at all three. However, there was also a contradiction at Corryhabbie and Strathfinella in the GPs' perception of the nurses providing diabetes care. As I will now go on to show, whilst the GPs claimed that nursing staff had taken on diabetes care because it was routine work, they also recognised these nurses as having greater expertise in this area than themselves and, to varying extents, deferred to their professional judgement.

Expert nurses and further reasons for the division of labour within the practices

Nurse's use of protocols in diabetes care did not begin with the introduction of QOF targets. At Corryhabbie the nurse-led clinic for diabetes reviews had been established four years before the introduction of the nGMS contract through the initiative of a practice nurse at that time. From the start, the provision of care had followed a practice-based protocol. Dr. Andrews commented that QOF had made care:

> Much more structured. The nurses have always been quite good at structuring things but with the QOF points behind them they sort of gather [force or momentum].

Having nurses structure and meet the targets for QOF was key to the contract success of Corryhabbie. Vicki's specialist knowledge and expertise were viewed as central. Dr. Shore described Vicki as the "lynchpin" in their diabetes service and also described how he would turn to her more expert knowledge even in questions of prescribing, which traditionally fall within the jurisdiction of the doctor:

> I saw a lady yesterday who since Vicki increased her Metformin has an uncontrollable diarrhoea… so I said, right, cut the Metformin back to the level that you coped with before and I put a note to Vicki… just asking what she wanted the lady on next.

Despite Dr. Shore's perception that nurses generally followed "humdrum and routine" protocols, he also acknowledged Vicki's higher level of expertise and deferred to, and trusted in, her clinical judgement. Vicki exercised clinical autonomy around making prescribing decisions in diabetes care.

At Strathfinella, Erica, had received the most recent training in diabetes, and, as at Corryhabbie, the GPs would refer to her specialist knowledge. For example, during my observation one of the GPs informally consulted Erica about whether people with diabetes were allowed to eat 'HobNobs' biscuits. However, Erica did not have a qualification to prescribe drugs like Vicki and was not the sole or dominant authority over diabetes as a clinical area. Decisions regarding patients' disease management and QOF targets remained shared with the GPs and prescribing continued to fall wholly within their jurisdiction. The division of labour reflected both where knowledge was viewed to be located and the historical precedent of a GP at Strathfinella taking the lead in diabetes care prior to Erica's employment. Erica performed the more routine elements of the taking bloods and tests for QOF in the interaction with the patient, whilst the professional discretion of clinical decisions remained largely with the GPs. However,

this also meant that Erica was the main clinician interacting with patients and hence addressing the psychosocial aspects of care.

Interestingly, the association of nurses with protocols and guidelines was not just expressed by the GPs at the three practices, but was also reflected in nurses' expression of their own identities. Most nurses that I interviewed tended to see guidelines as *the* central support or reason for a treatment; for example, Jenny, the practice nurse at Silvenea, commented that guidelines are "the backbone of our treatments".

The view that nurses follow protocols was also supported by the district nurses involved in my fieldwork at Corryhabbie, one of whom explained that she always stuck to the guidelines even though through experience she might know something else would work better. Similarly, Vicki, stated that everything she did in the diabetes clinic was justified by protocols:

> As a nurse who's doing the clinic, the doctors say, oh, you and your protocols and your guidelines, but it's the way that we're comfortable. It's our own, it's the only way we can do it because if we do something, we can say, that's what it says in the guidelines.

Like the doctors above she associated nursing identity with following protocols. Also like the doctors, nurses were generally positive about the increased attention to clinical targets and Vicki appreciated the extra authority that QOF gave her to pressure the doctors to pursue these targets.

> I was trying to achieve things and if you went and you said [to a GP] for example, cholesterol is 5.5, ach, it's nae bad, just leave it… whereas now, because of the contract, [the doctors are] quite happy to treat… we've really been quite aggressive in treating HbA_{1c}s… but I'm also a prescriber now.

Both the symbolic authority of the evidence based goals of QOF and its financial influence had given Vicki greater authority over the doctors to push for better biomedical treatments. This authority had recently been increased even further by her qualification as a nurse prescriber and thus potentially challenged the archetypical

professional jurisdictions of doctor and nurse. Indeed Vicki's identity had begun to be blurred with that of the doctors. Early in my fieldwork, when I asked the administrative staff to point out which doctor was which, one person included Vicki. This was met with a quick retort of "she's not a doctor but she thinks she is".

In contrast Erica, the practice nurse at Strathfinella, who had previously worked as a Macmillan nurse specialising in palliative care, did not link her identity as closely to guidelines. She commented that when she first started as a practice nurse two years earlier she found the contract "very constraining", limiting her ability to provide patient-centred care. Similarly, Jenny, the practice nurse at Silvenea, drew on nursing's 'traditional' holistic identity (Davies, 1995; May and Fleming, 1997) to suggest that the involvement of nurses would prevent QOF over-riding patient-centred care. She pointed out that as they were not (often) partners in the practice, these practice nurses did not reap any direct financial reward from meeting the clinical targets and, hence, according to Jenny, could continue to put the patient first.

From the perspective of the nurses, taking on diabetes clinics was viewed as appropriate for two slightly contradictory reasons: firstly, because guidelines and protocols were the "backbone" of their work, the adoption of specialist clinics and authority through QOF enables them to push doctors into providing 'better' clinical care; secondly, because of the independence of their pay from the QOF rewards (in these practices where only GPs were partners), they could provide more patient-centred care than the GPs.

Discussion of divisions of labour within the practices

According to Abbott's (1988, 33) "theory of the system of professions", each "profession is bound to particular tasks by ties of jurisdiction" over a particular area of work and esoteric knowledge. He suggests that professions exist within a dynamic hierarchical system in which they each compete to maintain and extend their jurisdiction by "poaching" tasks from other professional groups. As mentioned in my literature review, Abbott (1988) notes that when work is rendered routine its status is degraded

and it becomes a threat to the professional identity of its practitioners. In order to maintain their professional status the professionals must delegate this work to a subordinate profession.

I have shown above that meeting the QOF targets for diabetes care was generally perceived as routine and protocol driven. QOF was perceived as more restrictive to the exercise of clinical judgement, and a greater potential threat to clinical autonomy, than the clinical guidelines that preceded it. This, I suggested, was because of the way in which QOF targets enter the clinical encounter, demanding the clinician's attention through the computer-based system of patient notes, reminders and checklists. I showed that this had led to a number of strategies through which GPs had attempted to bracket out QOF from patient-centred care at each of the practices. The particular mode of "putting a circle" around QOF reflected the specific ethos of each practice, as demonstrated through the example of the depression indicators and the use of the computer systems. One strategy of limiting the influence of QOF on GPs' services was to delegate diabetes care to nurses.

In line with Abbott's (1988) theory, across the practices I have also shown that protocol-driven work was generally considered appropriate work for nurses. Hence, one might expect diabetes care to have been delegated to nurses at all three practices. However, this was not the case. At Silvenea Dr. Harrison suggested that diabetes care should not be carried out by a nurse because nurses would not have the broader clinical knowledge to distinguish between routine and non-routine cases. This argument, Abbott suggests, is the "only defence" which a profession can use when external forces render their work routine making it "an obvious target for poaching by other professions and for compulsory deprofessionalisation by the state" (1988, 51). Dr Harrison was also perhaps defending his professional jurisdiction over diabetes care as a part of the generalist ethos of general practice espoused at Silvenea, and his concern that his practice would cease to exist after his retirement. In addition, Silvenea had only employed a practice nurse (for four hours a week) the year before my fieldwork and there was no precedent for

delegating general practice work to a practice nurse, nor, given the relatively small population served by Silvenea surgery, was it considered necessary.

At both Corryhabbie and Strathfinella GPs claimed that diabetes care was routine work appropriate for nurses, but somewhat contradictorily, also claimed that the specific nurses at their practice had greater knowledge of diabetes than themselves and would defer to their expertise. Abbott argues that, whilst archetypical perceptions dominate generalised, public perceptions of professional roles, in most work settings "divisions of labour are established through negotiation and custom that embody situation specific rules of professional jurisdiction" (1988, 65). These shift and blur in order to meet changing organisational imperatives. So, the GPs' somewhat contradictory view of the nurses providing diabetes care might be attributed to a distinction between their views of the archetypical role of a nurse and the local divisions of labour with these specific nurses. This theory is supported by the slightly different roles these nurses adopted, which reflected the particular local and historical context of diabetes care at each practice. At the two practices GPs had differing levels of confidence in their own ability to provide diabetes care associated with the historical context of care being referred to the hospital clinic at Corryhabbie and long provided by a GP at Strathfinella. Also the practices had differing approaches to holism, with Corryhabbie adopting an approach where clinicians often specialised in one particular condition and their colleagues referred patients to them within the practice. Nurses' own perceptions of their identity also seemed to be related to balancing the provision of patient-centred care and applying clinical guidelines. McDonald et al.'s (2009) study of the impact of the nGMS contract on practice nurses suggested that there is a trend away from nurses espousing their traditional ideology of caring towards a more medical orientation of pursuing the biomedically defined QOF targets. By routinising aspects of medical practice, QOF is potentially readjusting the jurisdictional boundaries between doctors and nurses. However, what the data above shows is that the division of labour at each practice results from a negotiation of general perceptions of professional identity and the local context of the practice ethos and historical organisations of diabetes care.

Conclusion

In this chapter I have discussed which health professionals were involved in diabetes care in each case study both within and outwith the general practice. I have argued that differences in service organisation across the case studies can be explained with reference to several interacting factors. These include: the ongoing construction of professional identities in relation to the influence and interpretation of health policy within specific local and historical contexts; and the role of trust in mediating inter-professional working and preferences for particular sources of clinical evidence.

The organisation of care and the implementation of health policy in each case study were influenced by the enactment of professional identity which is related, as Abbott (1988) suggests, to the nature of the work itself. The historical organisation of diabetes care resulting from previous health policies also influenced the division of labour amongst clinicians based both within and outwith the practice, or at least how that division of labour was perceived. Similarly, perceptions of recently introduced health policy instruments such as MCNs, QOF and MCN clinical guidelines were both informed by, and informed stereotypes of professionals in 'other' sectors, and trust in those professionals. However, at Strathfinella and Silvenea these stereotypes were not applied to the case of individual professionals or practices. Perceptions of individual professionals were based on past experiences of them fulfilling expectations of their roles, providing competent care, and 'good' communication. These factors formed the basis of trust (or distrust) across professional boundaries and influenced expressed preferences for referring (or not referring) patients and for seeking clinical advice. This trust was characterised by instrumental expectations that the trusted clinician would fulfil the role expected of them competently, but also the axiological expectation that they would provide appropriate care and act for the patient's interests rather than their own. These relationships, and the trust they engendered, were also informed by the previous behaviour of other clinicians in relation to past health policies.

In the next chapter I will move on to focus on patients' experiences of receiving both generic general practice care and care for their diabetes in each case study. In particular I will discuss how the different organisations of the diabetes clinic in each general practice were perceived by the patients before moving on to discuss the interpretations of the organisation of diabetes care as a whole.

Chapter 6: Experiencing diabetes care as a part of "generic" general practice

Introduction

In the chapters four and five I outlined and offered possible explanations for the organisation of diabetes care across the three case studies drawing upon the perspective of the health professionals involved. In this chapter I turn my attention to the experiences and perceptions of the patients receiving diabetes care in each case study. In chapter four I suggested that the differing extents to which diabetes care was incorporated into everyday general practice or organised as a separate clinic within the practice was related to professionals' conceptualisations of holism and continuity of care. This chapter will reflect on the extent to which diabetes care was experienced by patients as incorporated into everyday general practice and the significance of this for their perceptions of their care. In subsequent chapters I will go on to reflect on how patients' perceptions of their diabetes and their role in its management may be related to the health care they received.

Perceptions of care and competence

Silvenea's generic general practice care

On the whole, the patients I interviewed at Silvenea were very keen to tell me how good they felt their general practice was. For example, right at the outset of his interview, Gregory stated that he thought Dr. Harrison was "brilliant as a GP". The following quotes summarise what the patients I interviewed felt about the service they received from Dr. Harrison and Silvenea Surgery as a whole:

> He's a very thorough man and I think he cares… that's the great thing, he really cares. He knows what he's doing and he does it because that's what he set out in life to do. (Gregory)
> Well, any problems at all… they just look after you, let's put it that way. (Ian)
> The concern's there to get you sorted out. (Carol)

Patients at Silvenea felt that Dr Harrison and his team took both a personal and a professional interest in their general well-being; he and the practice as a whole were perceived both to care about the patients and to be competent in providing that care. Several aspects of the general practice organisation contributed to patients' perceptions of care. For example, Joanna commented on the availability of the GP:

> It's excellent here. My family keep wanting me to move away but there's no way. Not with what's here. When I hear them down [at other practices] saying oh you can come in two weeks to see me... No. I can call [Dr Harrison] up and I can come in and can he see me? Yes he'll see me. It's just excellent.

The surgery's open access system, which made it quick and easy to see a GP, was highly appreciated by patients and was further enhanced by the practice's informal approach. For example, Joanna went on to tell me that when she was at the surgery to collect her prescription (Silvenea was a dispensing practice) Dr. Harrison had been known to ask her to come in for an impromptu consultation if she looked unwell whilst she was there.

The availability of the GP was generally highly valued by the patients and was a central aspect of the perceived high quality of the service. The personal approach to care at Silvenea also created a sense that the professionals cared about their patients; as Doreen put it: "they seem to be interested… I'm not just a number". Part of being treated like a person is that the patient perceived the health professionals and practice staff to be interested in their welfare. This feeling that one was being treated as a person was further enhanced by the belief that the GP knew you as a person in the local social context, as the following quote from Frances exemplifies:

> Well I think the care in the country is probably a lot better than the care they get in towns where they are busier. Dr. Harrison is very good. I mean he knows everybody. He knows his patients and he knows what goes on and everything.

Being known was a central aspect of what the patients at Silvenea presented as good care. It meant that Dr. Harrison was perceived to tailor his care to the individual needs,

or what Gregory termed the "quirks" of his patients. It created a sense of being cared about and was often placed in contrast to care experienced or heard about elsewhere, this was often associated with their rural location and small community. Patients commented that they felt, not only that their GP knew them, but also that they knew their GP, either socially or as the result of frequent health care encounters. This "mutual personal and contextual knowledge", or "connectedness" (Farmer, 2007, 226), also, I would suggest, contributed to patients' trust in their GP. For example, Carol commented that:

> I have complete faith in Dr Harrison. I got to know him pretty well when my husband was ill. And … I've known a lot of the girls [Susie the district nurse, the health care assistant and the practice manager] who are working up there since they were children here. I just know they're a very special bunch.

Davies and Rundall (2000) make a clear distinction between faith, dependency and trust. Unlike trust, they define "faith" as having no basis in prior experience or knowledge (Davies and Rundall, 2000). Whilst I will discuss this distinction further below, here I would just like to point out that Carol's expression of "faith" might also be viewed as trust. Carol's trust is based on past experience of Dr Harrison's care for herself and late husband and her personal knowledge of him and the other professionals at the surgery. However, this trust relies heavily on her personal knowledge of the professionals and perception of care, rather than any external measure by which she might judge the health professional's clinical competence. Carol's personal trust in Dr. Harrison was core to her perception of her care as a whole, and she described him as:

> The hub of it, and… the whole surgery are just sort of attached to him. They're part of him, they're his little channels coming out in different ways that are all helping him.

Patients at Silvenea generally perceived Dr. Harrison and the Silvenea team as caring and, on the basis of previous experience, providing, what they judged, to be competent care. Several of the patients I spoke to had either suffered severe illness in the past, such as heart attacks, or had had terminally ill family members who had received care from

Dr. Harrison. An example of this is taken from Gregory's account of being treated for severe chest pain:

> I drove down to the surgery… and I sort of staggered in… James came rushing out… "At your age", he said, "pains in the chest, hospital" he picked up the telephone and I was in hospital within half an hour… I'm not saying it wouldn't happen elsewhere but I'm saying that was him and, I'd been in for a couple of hours and somebody said to me, oh James Harrison's just rung to find out how you are and it struck me, you know, in other practices, how often does the doctor ever ring up and find out how his patient is… it's that feeling of confidence that's terribly important.

As Gregory mentions, although Dr Harrison's response may have been the standard procedure in response to a heart attack at any practice, the fact that the doctor rang later to see if he was ok gave him particular "confidence". This confidence, which I would argue might be understood as trust, was engendered through experience of competent practice combined with Gregory's perception that Dr Harrison also cared about him. Calling the hospital to ensure his patients were 'ok' seemed to be common practice for Dr. Harrison, as other patients told me he had done the same for them on similar occasions, and the similarly interpreted this as a sign of care.

All the patients I interviewed at Silvenea presented the practice as generally competent and caring, although, as I will discuss below, one patient did question the competence of the practice's diabetes care organisation.

Diabetes care

As outlined in chapter four, at Silvenea diabetes care differed organisationally from everyday general practice. Frances, explained that whilst for generic general practice they had an open access system so you did not have "have to make an appointment three days before you're going to die", for diabetes care the practice tried to "make a clinic" and "actually send you an appointment". Like Frances most patients approved of this arrangement. Frances went on to explain that having an appointment for diabetes care

was important because the various aspects of the review took longer than a normal consultation and she observed:

> It's not really fair… [to have] people waiting in the waiting room who want to see him…So, it is better from that point of view if you have an appointment really.

The differing organisation for the diabetes review was understood as existing to protect the highly valued open access system. The diabetes review appointment was also still carried out by Dr. Harrison. Hence, the various acts of measurement and monitoring which it involved were interpreted as just another sign of Dr. Harrison's "care of his patients", as Carol put it. Diabetes care was viewed as an integrated part of their general practice care because it was also provided by the same doctor; hence, it was both imbued with, and reinforced, perceptions of care and competence in other aspects of their general practice.

Patients perceived Dr. Harrison as "keeping an eye on" them, as Joanna put it. Similarly, Carol described Dr Harrison as keeping a "close watch" and Gregory quipped that he "takes a few gallons of blood and flogs it down the market or something" and "comes back with bits of paper saying, this is alright and that's alright, you know". Both Dr Harrison's regular provision of review appointments, and the regularity with which he and the nurses took blood samples, were seen as proof of the closeness of this monitoring and the competency of care.

The only exception to the general perception of care and competence at Silvenea was expressed by Steven, who told me that he did not understand the blood results from his diabetes review and would like a better explanation. In addition he "wondered whether [taking blood] once a year" was frequent enough to monitor his diabetes properly, questioning the competence of the care he was receiving at Silvenea. This exception might be attributed to two factors. Firstly, Steven was the only patient at Silvenea who had joined Diabetes UK and extensively researched his condition on the internet. Secondly, he was in his fifties whilst the other patients interviewed at Silvenea were all

over sixty, and previous research has suggested that younger patients tend to desire more information and involvement (Say et al., 2006). Steven wanted more explanation of the practices of monitoring his condition in order to inform his perception that he was receiving competent care, and hence provide a basis for his trust in the practice.

Corryhabbie's generic general practice care

Most of the patients at Corryhabbie were positive about the competence of the GP they recognised as their "own doctor", or saw on a regular basis. For example, Kathleen commented that the doctor she saw was a "wonderful diagnostician". However, perceptions of the care received from the staff at the practice and from some GPs were more negative. For example, I was repeatedly told that trying to make an appointment with a chosen doctor less than three weeks in advance was impossible, for example Susan commented:

> It's an absolute nightmare... ye honestly cannae get an appointment with the doctors. It's just a standing joke.

Moreover, the receptionists were perceived to be partly responsible for these difficulties, for example, Thomas described his recent attempts to get an appointment:

> I've been put off and put off by the woman on the desk and when I've finally got there, I turned round to the GP, I said, it's easier to get in to see the Queen than it is to get in to see you, because these jobs at the front are blocking everything.

Previous research (Tarrant et al., 2003), has found that receptionists can play an important role in creating a sense of receiving "personal care" from a general practice. However, at Corryhabbie the perception that the receptionists were deliberately trying to discourage patients from seeing their preferred GP had the opposite effect.

In addition, because appointments with specific doctors were difficult to make, patients complained that they could not maintain relational continuity; for example, George commented:

> You've to take who they prescribe nowadays. At one time, you just spoke to your own doctor and that was it. That doesn't happen now… I think it's only right you should see your own doctor but it doesn't happen.

George's comments suggest that he feels that he has no power to choose which doctor he sees and there was widespread frustration that patients could not maintain continuity with one doctor when they felt it was necessary. However, the need for continuity in their general health care was viewed in a more nuanced way than the difficulty of making appointments. Like previous research (Schers et al., 2002), I found that patients at Corryhabbie suggested that continuity of care was desirable for chronic conditions or general medical concerns, but for acute illnesses, being able to see any doctor was acceptable. Moreover, the availability of a second opinion was also appreciated at Corryhabbie. For example, Bert commented that he was disappointed that he could no longer see his own doctor but understood that "he's a very busy chap", and thought that "there's some merit in seeing somebody different, because they may well spot something that [was previously missed] and give you another opinion". Similarly, Thomas told me that he saw having several doctors as a clear advantage as it meant that he had "choice" and could seek a second opinion with another doctor if unsatisfied with the actions of the first.

However, overall, the current appointment system caused frustration because it did not facilitate continuity when it was desired in generic general practice and, interestingly, patients suggested various reasons for this. The most common explanation for the lack of continuity was given above by Bert, that the GP was simply too busy. This, some suggested, was because there were too many patients placing unjustified demands on the service. Notably, this explanation did not imply that their GP was no longer interested in their patient's welfare, merely that the service was overstretched. Other explanations suggested that continuity was no longer possible for other reasons; for example, Kathleen commented:

> The whole thing has changed because it used to be your doctor took responsibility for you, that's why we always used to see the same doctor cos

> he knew you … but nowadays you go in and it's all part and parcel of taking responsibility for your own health because if you're going up there and you're seeing any doctor, you can't expect them to know the things you've had and what may be wrong with you. You've just got to accept it. It's the change in the way of life.

Kathleen attempts to give the lack of continuity a positive slant, in that, as the rest of her interview demonstrated, she considered that people should take responsibility for their own health. However, her final comment, that "you've just got to accept it", suggests that she would at least like to have the choice to sometimes not take the responsibility for her own medical care. For both Bert and Kathleen the lack of continuity was not interpreted as an indication of a lack of professionals' interest or care about their well-being.

In contrast, Martha was much more critical of her professionals' motivations:

> They are getting such big pay that they don't work a full week now… There must be fourteen... doctors up there, but they are only doing 2 days. So, if you specifically want to see *a doctor* it'll be a month afore you can see 'em because they're only there two days a week. So you cannae stick with one doctor.

The reasons which patients proposed for the lack of continuity in their care reflected their interpretation of their professionals' motivations. Interpretations of other's motivations can form a basis for trust (Hardin, 1996; Möllering, 2006), but where health professionals were perceived to be motivated by self-interest rather than the needs of their patients, as in Martha's case, this basis of trust was lacking. However, established relationships between patients and their professionals also informed perceptions of the professional's motivations. For example, Bert had been registered at the practice for over forty years and had viewed Dr Shore as 'his' doctor for more than twenty of those. He had developed a (trusting) relationship with his doctor in the past, which, appeared to be why he did not hold Dr Shore responsible for his current difficulties in maintaining this continuity. In contrast, Kathleen described moving between several doctors over the course of being registered at Corryhabbie, and Martha related various experiences of

misdiagnoses by the GPs at Corryhabbie and had eventually been found to be suffering from quite a rare disease. These experiences had led her to question not only the GPs' and practice staff's care but also their competence:

> You can go there a hundred times and there is not a soul up there who can tell you what you've got… It's just hopeless… If it's very sore, take a painkiller. *You and I could be a doctor* cause that's all they ever do.

These experiences of misdiagnoses were combined in her interview with accounts of friends and family whom she also perceived to have received poor health care culminating in a very negative perception of the care and competence of the practice as a whole. Whilst Martha was exceptional in the extent to which she doubted the competence of the professionals at Corryhabbie, several of the other patients I interviewed also complained about what they perceived as the GPs' lack of interest or care about their health. For example, Thomas and David commented:

> You used to seem to be able to get longer with people… you could go and talk to them… but now they're not so much interested in your problem. They're more interested in trying to sort the problem out without even delving right into the depth of it. (Thomas)

> Some of the doctors can snub you or dunnae ken you, although all the information, your records is there in front of him its still you're nae a patient of mine sort thing, that feeling. (David)

With the exception of Martha, patients at Corryhabbie generally tended to continue to believe that individual clinicians were clinically competent. However, the organisation of the practice such that they could not easily make appointments left them feeling that their interests were not put first, that the staff at the practice in general did not care. Moreover, for some patients, interactions with individual clinicians added to the sense of a lack of care as several patients reported that appointments were short and, like Thomas and David, described their interactions with their GPs as impersonal in some way. Whilst the opportunity to seek a second opinion was appreciated, this was perhaps promoted by the negative aspects of the service. Interestingly, however, the negative

aspects which patients identified in the generic care at Corryhabbie were not reflected in their accounts of diabetes care.

Diabetes care

Until 2000, diabetes care at Corryhabbie had been provided at the hospital and all of the patients I interviewed (with the exception of Kathleen) continued to attend the hospital clinic in addition to the practice clinic. As described in chapter four, at the practice diabetes review appointments were arranged through a separate administrator to everyday general practice appointments, and all diabetes care was provided by Vicki who was at the practice two days a week to run the diabetes clinic.

The diabetes service at the practice was presented by patients as quite different from their experiences of generic general practice. Thomas explained that, with regard to "general medical things", the doctors and practice as a whole are not "interested", but "diabetic things is another can of worms altogether". Partly because of patients' experiences of the practice's generic health care, the separation of diabetes care from generic practice was generally considered a positive thing at Corryhabbie. Patients' accounts showed that many of the aspects which they felt were lacking in their generic care were provided in their diabetes care. In particular, patients contrasted the relational continuity and feeling that they 'knew' Vicki with their generic care:

> I've known Vicki for years. It's more a friendship nowadays, you know, which does make a difference if you're seeing the same person all the time. I think this is the problem with the health centre, I'm afraid. You very seldom get the same doctor. (George)

Most patients also expressed a preference for the practice diabetes clinic over the hospital clinic. For example, Thomas who received care from both the hospital and general practice, commented:

> I mean, she [Vicki] gives you a row and she's given me more than one row but that's what she's there for… she thinks she's doing the right thing by giving you a row. I've got nothing against her. In fact, it's quite a bit of fun

> going down there… I prefer that to go and see her than the hospital but I have to go to the hospital.

It is the personal interest which Vicki is perceived to show which weights Thomas' preference. Thomas interprets the "row" Vicki gives him as sign that she is genuinely interested in his well-being, caring. Although he went on in his interview to comment that Vicki had "forgotten" to send him an appointment for two years and then remembered him again, Thomas laughed this off. He, like all but one other patient I interviewed also received regular reviews in hospital and, perhaps because of this, he was not too concerned about having been "forgotten" by Vicki. However, this did perhaps contribute to his view that he "had to" attend hospital appointments and that the hospital "was in charge". Similarly, Bert, who had been diagnosed over thirty years ago, also commented that:

> I look on it that since we've had to go down to the health centre, it's been an extra. It hasn't stopped at the hospital and started down here.
> **HM: Would you be happy if the health centre replaced the hospital completely?**
> Aye I suppose it's certainly handy, it's not so much of a problem then organising transport in and out but, apart from that, I dare say there's some merit in going into the hospital where they're obviously more highly trained and so forth.

As found elsewhere, (Lawton et al., 2005; Lawton et al., 2009; Murphy et al., 1992), care in general practice was also preferred for its convenience, but the hospital professionals were perceived to have greater expertise. As Bert went on to comment, the role of the practice was "keeping a check on you and so forth… if there was something different then they would spot it", whilst the hospital professionals were "more highly trained". In addition, the practice diabetes clinic was viewed as better organised than the hospital's which, as Susan observed "could be run better", a view expressed by all who received care there but Martha. One patient, George, went so far as to comment that the hospital clinic would "scare" me because of the "queue about a mile long" and you had to wait the two and a half hours before you were seen. Patients drew comparisons between the benefits of the practice based clinic and the hospital, which usually resulted

in them expressing a preference for the practice clinic. Perceptions of the care and competence of the Corryhabbie clinic were derived through comparisons with both their generic general practice and the hospital clinic.

Patients informed me that in comparison to everyday general practice, diabetes appointments were easy to rearrange if offered on inconvenient dates. For example, Susan told me she frequently needed to change her appointments to fit with her shift work but always got an "appointment nae problem if" she changed. In addition, several patients commented that Vicki was easily accessible by telephone two days a week should they have any concerns or queries. However, they did face difficulties if they needed advice on the other 5 days. All but one patient at Corryhabbie presented the diabetes care they received in the practice as convenient, competent and caring, enabling the access and continuity of care which was difficult in their generic general practice service. The one person who expressed a preference for staying in hospital only care was Martha, who, as I mentioned above, was generally disillusioned with health care at Corryhabbie.

Interestingly, however, the exception of Martha, further supports my argument that patients preferred to receive their diabetes care from a professional they felt they could trust on the basis of perceptions of their care and competence. Martha's reasons for wanting to stay with hospital care were similar to those of the other patients for preferring to receive their care at the practice clinic. Firstly, she commented that the poor organisation of the clinic and irregular review appointments were not "very satisfactory" if Vicki was "supposed to be keeping an eye on your diabetes". Secondly she did not view Vicki was either caring or competent, and commented that Vicki "never seems to me to ever give you any comfort, any praise", and that she "would question it" because she did not seem to have "much knowledge of what she's speaking about". In contrast however, Martha expressed her preference for the hospital clinic in terms of the care and competence she perceived her consultant to have demonstrated over the twelve years she had attended his clinic:

> You've confidence in him. That's what it is you know. Well just his manner, I think is what does it. He'll speak to you about anything that you want to speak about. And you feel that anything that he tells you is the right thing because of who he is.

As observed elsewhere (Mechanic and Meyer, 2000), perceptions of knowledge and competence are based on both professional credentials and personal cues and rapport. Martha's assessment of Vicki's competence seems to have been partly informed by her poor personal relationship with her. Although most patients I interviewed at Corryhabbie presented themselves as having a good rapport with Vicki, Martha was not alone in her criticism. The variation between patients at Corryhabbie may be because they had differing experiences of receiving care in hospital to draw comparisons of Vicki's approach with. Hence, patients' past (variable) experiences of care in hospital informed their perception of their care at the practice.

As mentioned above, all the patients I interviewed bar one continued to receive care from both the hospital and Corryhabbie. This meant that a larger number of health professionals were involved in providing diabetes care at Corryhabbie than was generally the case for patients in the other case studies. Most of the patients told me that they thought that Vicki was aware of any changes that the hospital had made to their medication and the results of blood tests taken in hospital. With the exception of Martha, whose consultant had questioned Vicki's prescription of gliclazide, patients also told me that they had not received conflicting advice from Vicki and the Hospital. Thomas discussed the extent to which the various professionals involved in his diabetes management seemed to communicate:

> They seem to communicate well between each other. I'm not sure whether the GP communicates too well but the others do. Cos, Vicki wanted to put me on some of these weight reducing pills and the GP wouldn't do it... So as I say, I don't think they - she communicates well with the other… the interaction between the hospital and Vicki is a lot better.

Interestingly, despite the fact that Vicki is based at the health centre, Thomas interprets his GP's decision not to put him on the tablets Vicki requested as a sign of poor

communication within the practice. He seems to see his diabetes care as better coordinated with the hospital than the general practice. The fact that prescribing was discussed between Vicki and his own GP suggests to me that there was communication between Vicki and the GP, if not agreement. However, Thomas' interpretation maintains a perceived division between diabetes care on the one hand (hospital and Vicki's clinic) and his general practice on the other. The patients I interviewed at Corryhabbie did not present diabetes care as yet another aspect of general practice. Most viewed it as something separate, an addition to their hospital based diabetes care rather than an extra to the practice. Even Kathleen, who was the only person I interviewed who had never attended the hospital clinic, presented Vicki's clinic as something separate, providing a specialist area of care because "you can't expect a doctor to have specialist areas all over the place". This separation from everyday general practice was perceived positively by most who appreciated that it enabled appointments to be made easily and provided the opportunity for continuity of care, which was difficult in everyday general practice. Negative experiences of Vicki's clinic tended to be associated with the communication between Vicki and individual patients as in Martha's case, rather than with the organisation of the clinic as integrated, or not, into generic general practice.

Strathfinella's generic general practice care

Most of the patients at Strathfinella were very positive about the care they received from the practice as a whole. Joyce summed up the general feeling about what was good about the practice in the following quote, where she draws comparisons between Strathfinella and the larger practice in the next town, which she knew through her work at the local care home:

> I like it… you get appointments just like that, you know, it's great... Down in [the next town] is a joke, you know, cos they have a lot of people… It's just more homely and friendly. I've always found it that way… I would never change, cos I get on well with all the doctors.

I was told by all patients that appointments were easy to make at Strathfinella and most shared Joyce's assessment that all the staff at the practice were "very helpful if you've got any problems or, you need help with anything". Several patients pointed out that the attitude of the reception team really contributed to their overall evaluation of the practice; for example, Jonathan commented that; "they will go out of their way to help you… there's very few practices with receptionists like that".

Moreover, Jonathan viewed the approach of the practice as a whole as personal. He reflected on the clinicians at the practice commenting that:

> I really can't fault them… They appear to care about the patients. That's the feeling you get… they do give you the feeling that they're there for you and you're not there for them which is good.

Most of the patients told me that they got on well with at least one health professional out of the four doctors and two practice nurses, and in every day care they were generally able to make an appointment with their preferred professional. Also, no one mentioned any problems maintaining relational continuity. Indeed, one patient, Jack, commented that, although he wanted to retire to Spain, he had chosen to commute between Strathfinella and Spain in order to maintain the care and continuity he received at the practice.

However, despite patients' comments on the friendliness of the practice as a whole, some bemoaned the loss of an even more personal care which they felt they used to receive from the doctors:

> It was more personal in the olden days and more friendly… I could really feel comfortable with the old doctors. (Katherine)
> Dr Scott, she's too abrupt for me, she doesn't seem to be wanting to be bothered… she gives you a prescription and off you go but I don't like that. I liked Dr Sinclair [who was now retired], I think she spoiled us all because she sat and she would listen to anybody, it didn't matter how long you wanted to sit, you could sit and she would listen to you forever but Dr Scott, no. (Margaret)

Both Katherine and Margaret complained that the relationship with the GPs at Strathfinella had changed over the 20 years that they had been registered at the practice. Margaret's criticisms were not limited to Dr. Scott, she generally bemoaned the loss of a more personal consultation which had seemed unpressured by time constraints. Interestingly, for these two women the role of the old GPs seemed to have been replaced by a preference for consulting with Erica or the other practice nurse. For example, Margaret commented:

> I go to Erica. I find her more approachable than any of the rest of them put together. But I mean, there are some times like when I had the boils, I had to have a doctor then, but I prefer to see Erica.

Margaret went on to outline various reasons why she did not like to consult with three out of the four GPs and was withholding judgement on the fourth, whom she had only seen once. All of her reasons focused around communication difficulties or personal character clashes on an individual level, rather than organisational features of the practice as a whole. Similarly Katherine expressed a preference for consulting with Erica or another nurse for her general health concerns for reasons of communication:

> Well, the doctor they talk to you, you know as if they're far better than what you are but the nurses talk to you as if they were old friends.

Both women felt that they could talk more easily with Erica, as she seemed to take time and listen, giving the impression of caring about the patient, of being "bothered" or interested in their well-being, seemingly caring about them.

In addition to feeling that the GPs were now less "friendly" than those in the past, Katherine went on to tell me that her neighbour had left the practice because they felt they were not treated as a person. She told me that her friend felt that being a Strathfinella patient meant that "you were just something that they give tablets to, [which] they got money from the government for". Katherine agreed with her friend and repeated that the current doctors did not "give enough attention to a person at all; it's only money that they're interested in".

Although not a widely held view, this suggests that there was perhaps an increasing concern, that professionals were being financially motivated to do particular tasks rather than listening and taking an interest. Katherine also told me several stories of misdiagnoses which had been made by the health professionals at Strathfinella and was therefore also concerned with the level of their professional competence. She commented that "somebody else always knows what's wrong with me except my own doctors." However, unlike her friend, she had not yet moved practice because she was happy to consult with Erica.

Another patient, Catriona, complained that she thought her health professionals' care was being constrained by the system of the NHS as a whole:

> I have to say, they pay great attention to every quantitative, piece of information they can get and they do listen. They try to understand what I'm saying and they make it even personal… they do come to conclusions about the overall, picture of the person... So I think they are good. But they are bound by… silly things like… 'I'm supposed to get through every patient in 10 minutes'. That's the kind of thing that… is totally foreign to any one who's really interested in practising medicine... that's all about money.

Katherine and Catriona both perceived limitations in the care they received, which they attributed to wider changes in the approach of the NHS, to paying GPs and limiting the time available in appointments. However, like the explanations for a lack of continuity of care at Corryhabbie, the perceived motivations of the doctors differed in Katherine and Catriona's complaints. Whilst Catriona continued to view individual health professionals as motivated to act in her best interests Katherine did not. This may be because Katherine had had other negative experiences of misdiagnoses at Strathfinella which had undermined her trust in the professionals there and coloured her perception of their motivations and the possibility of her placing trust in them in the future.

Diabetes Care

At Strathfinella the practice nurse, Erica, carried out all of the diabetes review appointments with patients during which she took blood and carried out the various

screening procedures. Erica then discussed the results of this review with Dr. Scott and patients were invited to an appointment with Dr. Scott only if there was some change. All patients bar one talked about Erica discussing their results with Dr. Scott and all told me that they received a letter informing them of their results and asking them to see Dr. Scott if there were any changes.

The patients I interviewed all agreed that Erica was "very easy to talk to" (Jeremy), and was "trained to look for what she has to look for" (Jack). However, the extent of her knowledge tended to be viewed as limited to the monitoring of the condition rather than having any specialist knowledge or making clinical decisions. This was particularly true in the comparisons which Joyce drew between Erica and the hospital clinic:

> Erica is good, she is very good, but it just doesn't feel the same… cos you can go and see Erica for lots of things, not just diabetes... Up there [at the hospital], it was just specifically diabetes.

Partly because Erica provided generic general practice care as well as diabetes care, she was perceived to hold less specialist knowledge. Although organised through a patient recall system and provided in extended appointments, diabetes care was not perceived as separate from generic general practice at Strathfinella. This was partly because it was provided by a clinician who also provided generic healthcare, and partly because appointments were not organised into a clinic which happened at a particular time.

As in the other two case studies, the view that the nurse's role was to monitor, 'keep an eye' on patients' diabetes, was prevalent at Strathfinella. Also, as in the other two cases, the organisation of regular reviews created a sense that the practice was both competent and acting in the patients' best interests. For example, Joyce explained that for her diabetes appointments she was phoned by the receptionist at work and if she were more than 10 minutes late for an appointment Erica would ring her work to find out what had happened. I asked her whether she appreciated being 'chased' to attend diabetes appointments:

> It's good. It shows they're on the ball, doesn't it, really? But I do moan a bit, God not again… but yeah, I do appreciate it. It's showing that they care really, isn't it? That they're doing their job. So definitely.

In addition, she went on to point out that if she had any concerns Erica and Dr. Scott "were just on the other end of the line"; all she had to do was call the surgery.

As mentioned in previous chapters, one GP had run a diabetes clinic at Strathfinella for the past twenty years. However, this organisation of care had recently changed so that the diabetes clinic was now being run by the nurse. This organisation of the diabetes review was generally approved of by the patients at Strathfinella and Joyce explained what she felt had improved:

> Before they changed it, I'd have the nurse and then the doctor straight after, so that was 2 appointments in one, you know, so that was half an hour… I don't have to see Dr Scott at all now, just the nurse like for 15, 20 minutes now, you know, and actually we're talking more… I only see the nurse now.

None of the patients I interviewed bemoaned the loss of having their routine diabetes review with the GP and Joyce, who was in her thirties, appreciated the shorter appointment as it was less disruptive for her work. Jack also thought that the change was an improvement, but as a retired man, he was not concerned about the time the appointment took. Rather he explained how he understood the system to work:

> [Following your appointment] they send the blood away, then the nurse, when they get the results back, discusses it with the doctor and then she'll just send me a letter saying 'no change in medication and giving me the results, of the various things'… So it seems to me it's more important the doctor [spends time seeing] somebody that's really ill or whatever, and then if there's anything wrong, they'd discuss it when yer bloods come back.

Jack was currently asymptomatic and, because he was aware that the doctor and nurse discuss his blood test results to identify if anything is "wrong", he trusted that he would see the GP when it was needed. Since Erica was viewed as competent in carrying out the clinical tasks of the review and was particularly approachable, patients were happy to have their review appointment with only her. The fact that she also discussed results

with Dr. Scott added to the perceived thoroughness of the review appointment. However, as observed elsewhere (Lawton et al., 2009), because patients did not see their usual GP for diabetes care, some had become unsure whether they could go to see their usual GP for other aspects of their healthcare or whether they had been moved onto Dr Scott's list. For example, Margaret commented that if she had any concerns she would turn to Erica before Dr Scott, but seemed unsure whether Dr Scott, or her choice, Dr. Macleod, was now her 'own' GP:

> I was supposed to be [with] Connor Macleod. He was my doctor up until I got diabetic and then I was shifted to Dr Scott.

Margaret was also confused and upset by the recent involvement of Dr. Gion in her diabetes care:

> I mean, I just got myself so worked up… because someone… had said to me that Dr Gion sent the letter to [my consultant diabetologist]. Now, I was incensed by that because it's nothing to do with Dr Gion. He's not my diabetic doctor. Dr Scott is my diabetic doctor. So I was incensed by that.

In contrast to the organisation of generic care at the practice, patients were not offered any choice regarding which GP would be involved in their diabetes care, nor did they seem to be informed of changes to this. Whilst diabetes care was not viewed as entirely separate from the generic care offered at the surgery as a whole, it was equally not integrated into the 'holistic' care provided by a chosen or preferred professional. As most patients had a good rapport with Erica this was not generally viewed as problematic, with the exception of Catriona who was concerned that her various illnesses were not being considered as a whole and hence not fully investigated:

> [The clinic] is a very efficient and very dependable mechanism. There's a practice nurse who specialises, there's a regular check up, all of that is very well organised. It will do the main things you want to do, which is… the little set of tests that they do… and they get to know the patient and they know about the other things. What they don't know… is, [why]… this person since having diabetes has now had, lupus and, a bypass and has now arteriosclerosis… It's a lot to take on.

Catriona suggests that she would like a more holistic and investigative approach and she also wanted to be referred to a specialist who might be able to explain the relationship between her conditions. For Catriona, part of the expectation of competent health care is considering the patients' various ailments together rather than segregating off each condition individually, which the organisation of separate clinics seemed in danger of doing.

In general, at Strathfinella diabetes care was perceived as part of the general practice care because: it was provided by Erica, who also provided care for other concerns, because appointments were arranged for anytime, and because patients had prior experiences of receiving diabetes care in general practice. However, the diabetes clinic seemed to be perceived as sitting on the edge of every day general practice because care was not provided by the patient's usual GP and they were not offered a choice of professional like they were for their generic care. This also was perceived by Catriona as limiting an integrated consideration of her illnesses.

Diabetes care as part of 'generic and holistic' general practice.

Patients' accounts of the care they received in each case study are consistent with the approach of the professionals in each case, which I outlined in chapter four. For example, professionals' emphasis on personal knowledge at Silvenea is reflected in patients' accounts of being known by and knowing their GP. Similarly, at Corryhabbie, patients' accounts of the appointment system reflected the professionals' lack of emphasis on providing relational continuity for everyday general practice. However, patients were perhaps more frustrated and concerned by the lack of continuity in their generic care. To a small extent patients also reflected some of the practice's ethos of the patient as a 'customer', being able to choose to seek a second opinion and, as Kathleen saw it, taking responsibility for their own health. At Strathfinella, patients' accounts of feeling that the clinicians at the practice took an interest in their wellbeing reflects the continuing emphasis on patient-centred care at this practice. However, patients' accounts

reporting changes in the nature of consultations and general practice are also congruent with tensions professionals described in trying to provide patient-centred care and meeting the demands of the nGMS contract.

As outlined in chapter four, one of the key policy aims of providing diabetes care in primary care was for it to be incorporated into the "generic and holistic approach" of general practice (Scottish Executive, 2003, 36). What is apparent from the data presented above is that moving diabetes care into general practice does not necessarily mean that it is experienced by patients as incorporated into a generic and holistic approach to care, and similar observations have been made elsewhere (Lawton, 2009).

My findings add that the extent to which patients experienced their diabetes care as part of generic general practice was dependent on the specific organisation of the service at their general practice and their past experiences of diabetes care. So, at Silvenea although patients recognised the diabetes review appointment was arranged differently from everyday care, it was also perceived as part of their generic care because it was provided by their usual GP. In contrast, at Corryhabbie, diabetes care had, for the majority of patients I interviewed, always been provided outwith general practice. Their past experiences, alongside the particular organisation of the clinic, which arranged appointments independently and was provided by a nurse, who patients consulted only for diabetes, informed the perception that the diabetes clinic was still separate. Finally, the extent to which patients viewed diabetes care as incorporated into general practice at Strathfinella lay somewhere between Silvenea and Corryhabbie. It was not viewed as quite as separated out as at Corryhabbie. This, I would suggest, is partly because the clinician providing care also saw patients for other concerns and patients had prior experience of a diabetes clinic being run in the practice. It was also partly because diabetes appointments were arranged through the same receptionists patients contacted for other appointments. Equally, however, as care was not necessarily provided by a patient's preferred GP it was not perceived as incorporated into generic general practice care, unlike Silvenea.

In all three practices the organisation of diabetes care was considered by patients in relation to the context of generic care at the practice and previous experiences of receiving diabetes care. However, what emerged as particularly significant in patients' accounts was not the extent to which diabetes care was incorporated into generic general practice, but whether the professionals providing diabetes services seemed to care and appeared competent to give appropriate care, which could be facilitated by feeling that one was 'known' to the clinician and had a good rapport with them. Policy has seemed to wrongly assume that these factors would follow on from providing diabetes care in general practice without considering the diversity within general practice itself.

Positive perceptions of care from the practice were enhanced by the approach of the reception staff and the ease of access to, and maintaining relational continuity with, a health professional who took time to listen, seemed interested in, and concerned about the welfare of the patient. Previous research (Tarrant et al., 2003) has identified similar factors informing patients' and providers' perceptions of "personal care", and, like this research, my findings suggest that perceptions of care are informed by interactions with the practice as a whole, and the way in which care was organised, and not just with individual health professionals. Other research has also already highlighted diabetes patients' preferences for relational continuity. Having a relationship with a provider who knows and understands them and was interested and had time to listen, whilst also being able to seek a second opinion, have all previously been identified as informing patients' preferences for diabetes care (Alazri et al., 2006; Naithani et al., 2006). My research adds to this body of work the observation that patients' perceptions that a professional was acting out of financial motivation, rather than on the basis of their best interests could undermine a sense of care, and so undermine a basis of trust.

As noted elsewhere, (Guthrie, 2008; Hall et al., 2001; Mechanic and Meyer, 2000) I also found perceptions of competence were related to inter-personal cues of seeming to care about the patient. The clinician seemingly "keeping an eye" on the patient through regular monitoring of their condition can enhance patients' perceptions that their

professionals are competent (as did the perceived expertise of a professional, which I will discuss further in the next chapter). Patients may assess a professional's competence by drawing comparisons between their approach or understanding and that previously experienced elsewhere.

The data presented in this chapter shows that, depending on the context of the practice, perceptions of care and competence can be facilitated by either incorporating diabetes care into everyday general practice, or organising it as something separate. At Silvenea where patients perceived diabetes care as part of their generic general practice and perceived the above criteria of personal care and competence to be provided in their generic care, diabetes care was viewed as part of the same approach. In contrast, at Corryhabbie where aspects of this personal care, such as the opportunity for relational continuity, were generally viewed as less common in everyday practice, the separation of the diabetes clinic was not questioned. This was because it could provide these aspects of care, and because patients' also received diabetes care outwith general practice, and so already perceived it as separate. Similarly, at Strathfinella, most patients did not suggest that diabetes care should be provided by their usual GP. Whilst care and competence were valued by patients in all cases, whether these were facilitated by incorporating diabetes into general practice differed depending on the practice context and the particular relationship between individual patients and professionals. Moreover, I would like to suggest that these experiences of care and competence acted as a basis for patients' trust in their health professionals.

Patients' accounts of care and competence as expressions of trust

I did not anticipate the significance of trust whilst carrying out my interviews and so did not explicitly ask patients whether they trusted their GP and/or their usual diabetes care provider. However, studies of patients' trust in health care have generally agreed that patients trust involves two expectations: that a health professional being clinically competent and that they will care or act in the patients' best interests (Brownlie et al., 2008; Calnan and Rowe, 2004; Davies and Rundall, 2000; Guthrie, 2008; Sztompka,

1999, 53). This trust has been also shown to be partly based on various factors but most notably previous experience of these expectations being met (Mechanic and Meyer, 2000). For example, Tarrant et al.'s (2008) questionnaire study of patients in UK general practice suggested that "inter-personal care, past experience of co-operation, and expectation of continuing care" are independent predictors of patients' trust in their health professionals. Tarrant (2008) argues that positive experiences of care in the past create a "shadow of the future" and a basis for trust in the future. Other studies have also suggested that trust can be facilitated by: continuity of care, and professionals sharing information (Calnan and Rowe, 2004). Patients having the opportunity to discuss and negotiate treatment options have also been associated with trust however, this is not always the case as trust has also been associated with patients preferring a passive role in clinical decisions (cf. Calnan and Rowe, 2004). Drawing on Möllering's theory, Brownlie and Howson's (2005) study of parents' trust in professionals' advice regarding the MMR vaccine for their children has also added to this by highlighting the processual nature of building trust drawing on multiple layers of bases. They suggest that trust based on access to clinical knowledge, or links to institutions, should be considered a precondition, a "warrant of trust" which "anticipates a process of trust building" through an inter-personal relationship over time (Brownlie and Howson, 2005, 229).

As I have discussed above, patients in my study described their experiences of general practice and diabetes care in reference to whether their expectations of care and competence had been met. They usually exemplified this with accounts of several healthcare encounters which discussed many of the aspects of care shown to be related to trust in the literature. Moreover, some patients used terms of "faith", "confidence" and "friendship" to describe their relationships with health professionals. I have interpreted these phrases and patients' accounts of their experiences of the care and competence of their health professional as expressions of trust, or a lack there of.

Patients' trusting expectations of their health care providers incorporate all three of the differing varieties of trust identified by Sztompka (1999, 54). They are instrumental in

that patients expect their clinician to be clinically competent and informed; they are axiological in that patients expect their clinicians to meet the moral expectations of their role as a doctor; and they are also fiduciary in that patients' expectation of *care* involves health professionals taking the patient's best interests as the basis of their actions. The nature of patients' trust in each of the three case studies and the role it played in their interpretations and preferences for health care will be developed further in subsequent chapters and discussed more fully in the final chapter of the thesis.

Summary and Conclusion

In this chapter I have presented patients' perceptions of the three general practices as a whole and the diabetes clinic organised by each. It is well recognised that patients' expectations of, preferences for, and satisfaction with health care are informed by their previous experiences of health services (Thompson and Suñol, 1995). I have argued that patients' expectations and preferences for diabetes care organisation in general practice are influenced by their previous experiences of receiving generic care from that practice generally and care for their diabetes.

Although diabetes care was not experienced by patients as part of their "generic and holistic" general practice care in all cases, the perception that the health professional and practice clinic organisation were both caring and competent seemed to be valued above incorporating diabetes care into generic general practice. Indeed, at Corryhabbie the separation of the two was generally considered an advantage. Perceptions that one was cared about across all three case studies seemed to be related to factors such as: the approach of the reception staff, the accessibility of the health professionals, the possibility of maintaining relational continuity with a particular professional, the perception that the professional was interested and took time to listen, and, finally, perceptions of the motivations of the professional's actions; i.e. whether this was financial or not. Similar factors have been found to underpin perceptions of "personal care" in general practice (Tarrant et al., 2003). Perceptions of competence in diabetes

care were related to perceptions of care, but also, professional credentials, previous experiences of receiving effective treatment for other conditions from those health professionals, and the apparent specialisation of the professional.

Finally, I have suggested that patients' descriptions of receiving caring and competent general practice and diabetes care formed the basis of trust or distrust in the particular clinicians providing those services. This trust was based largely on experiences of receiving care over time. In the next chapter I will go on to discuss the various ways in which patients interpreted the organisation of their care and perceived the multiple health professionals involved to have differing levels of expertise. In particular, I will focus on the ways in which the organisation of care was interpreted by patients as an indication of the state of their diabetes.

Chapter 7: Perceptions of disease progression and severity

Introduction

In the previous chapter I considered whether patients experienced their diabetes care as incorporated into everyday general practice. I argued that patients' perceptions of receiving caring and competent health services were central to their preference for diabetes care, rather than whether this was integrated into general practice or not.

In this chapter I will move on to consider how the organisation of diabetes services in each case study might influence patients' perceptions of the progression and severity of their condition. In doing this I aim to build on Lawton et al.'s (2005b) research, which highlighted some of the ways in which asymptomatic patients newly diagnosed with type 2 diabetes could interpret the organisation of their care as an indicator of the severity or progression of their condition. Lawton et al. (2005b) found that being referred from primary to secondary care was interpreted by some patients as a sign of having a more serious condition. Others interpreted not being referred into secondary care as a sign that their condition was not particularly serious after all, or being discharged back into primary care as an indication of improvement (Lawton et al., 2005b). Patients, who for other reasons, viewed their condition as serious, were found to prefer to receive diabetes care in hospital (Lawton et al., 2005b). Hence, Lawton et al. (2005b) suggested that there is a dynamic relationship between patients' perceptions of their condition and their experience and perceptions of the organisation of their health care. However, Lawton et al.'s study (2005b) focused only on patients' interpretations of receiving care in either primary or secondary care settings, and did not consider the ways in which patients might also attribute meaning to the organisation of care in primary care itself.

In this chapter I will argue that patients' perceptions of their health care organisation and, particularly, differing professionals' expertise in diabetes are constructed partly in

relation to the local context and their past experiences. This in turn meant patients' interpretations of the organisation of their care as an external indicator of the state of their condition varied across the case studies. In addition, the meanings attributed to changes in that care organisation, or a lack of change, seemed to be mediated by the trust the patient had in the professional initiating those changes or not. However, patients' perceptions of their condition's severity and progression are also influenced by multiple other factors which have been identified in previous research and it is necessary to consider how these factors may have influenced patients' perceptions of their condition before I can consider the influence that interpretations of diabetes service organisation might also have had.

Factors influencing patients' perceptions of their diabetes

Previous research has highlighted that patients' perceptions of the progression and severity of type 2 diabetes are informed by multiple factors. Not surprisingly, the experience of physical changes, such as the onset of the disease complications, has been identified by patients as a key indication of disease progression and severity (Murphy and Kinmonth, 1995; Savoca et al., 2004). Initiating insulin has been shown many times to be associated with feelings of failing to halt the progression of the disease and a sign of having a more 'serious' condition (Nakar et al., 2006; Peyrot et al., 2005; Polonsky et al., 2005; Snoek, 2002). In addition, starting to take oral glucose lowering agents (OGLAs) can be viewed as an indication of disease progression (Lawton et al., 2008). As noted in relation to other chronic illnesses (Pound et al., 1998; Sanders et al., 2002), the point in a person's life at which they were diagnosed has also been found to influence patients' perceptions of their condition. Savoca et al. (2004) found that older people tend to view the condition as less serious, whilst those who had witnessed friends and family suffering from diabetes and its complications tended to view the condition as more severe and were more motivated in following their prescribed regimens of self-care. As I will now outline, my research generally supports these earlier findings.

Biography

Across the three case studies patients' perceptions of the progression and severity of their diabetes were related to many of the factors identified in earlier research. For example, those patients who had been diagnosed in their sixties or older tended to attribute their condition to their age and viewed it as one of the "less" serious illnesses which might be anticipated as one got older. Carol, who was a patient at Silvenea and had been diagnosed when she was in her early eighties, summed this position up:

> In the run of things, it's not a bad thing to have compared to what you could have… if I'd had it when I was younger, I might have thought differently.

Other patients who had survived serious illness, or had partners or close family who suffered from other serious illnesses, such as stroke, comas, cancer, and multiple sclerosis, similarly tended to view diabetes as one of the less serious illnesses. Perceptions of diabetes are relative to previous experiences of health and illness and expectations of illness in older age. Alongside this, most of the patients I interviewed also recognised the potential severity of diabetes and knew that it was a condition which could lead to complications such as blindness, amputations, and heart disease. However, these were also viewed as something which could be put off or avoided all together; for example, Jonathan commented:

> People have trouble, and they can lose limbs and they can go blind… It's a killer… But, if you're relatively sensible, I think you can handle it.

The progressive nature of diabetes was under-emphasised by patients in favour of a discourse of the patient's responsibility of maintaining 'control'. This meant both maintaining glycaemic control but also control of symptoms and side-effects of medications. Hence, whilst it meant an increased risk of developing long-term complications, the several insulin treated patients I interviewed described keeping their blood glucose level slightly over the recommended level in order to avoid hypoglycaemia. Joyce exemplified this:

> Mine's always just a little bit high. It's a comfort zone sorta thing, isn't it? Cos low frightens me… It's a feeling and it's so horrible… But yeah, I know, slightly high you do get [problems], but, [I've had] just the thirst and the tiredness… I just feel a wee bit safe when the sugars just been that slightly bit higher.

Patients' preference for limiting the immediate risk of hypoglycaemia over the long term risk of complications arising from hyperglycaemia have been long recognised (Drummond and Mason, 1990, 45), but it is worth remembering that from the patient's perspective 'control' has multiple meanings (Hunt and Arar, 2001), and equally, disease progression was indicated in multiple ways. Patients' perceptions of the progression of the condition could involve both an increased rate of "hypos" as well as the onset of complications, as is exemplified by Bert's reflections on his own diabetes 'control' over the past forty years and his recent frequent experiences of unconsciousness from hypoglycaemia:

> In retrospect I could have done more towards controlling my diabetes and maybe if I'd done that I maybe wouldn't be troubled with hypos and so forth as I am now.

Medications

As found elsewhere, insulin initiation was also widely viewed as a sign of disease progression and more 'severe' form of diabetes across the case studies. For example, Ian, who was not using insulin himself, responded to my question about whether he considered diabetes a severe illness, by saying:

> Well, it's severe for some, obviously the ones when they have to take needles and things, it's severe for them cos there's a fella just up the road here, he's on it and he's collapsed a few times with it… that's pretty serious. That's why I look after my side of it. As long as I can keep it as it is, I've no worries.

This association between insulin and severe diabetes was not, however, shared by all. Steven who was a member of Diabetes UK and had researched his condition on the internet, and Susan, who was a nurse who occasionally treated patients with diabetes,

both emphasised that diabetes was a serious condition whether one was using insulin or not. For example, Steven commented:

> I think a lot of people have the wrong idea, thinking that diabetes isn't serious because you're not injecting insulin…You know, even though I don't take pills or inject insulin, it's still a serious condition.

Other changes in disease management regimens, such as starting to use oral glucose lowering agents (OGLAs), were also interpreted as indications of disease progression. Twelve out of the 23 patients interviewed in this study were using one or a combination of OGLAs. As found elsewhere (Lawton et al., 2008), patients could interpret tablets as proof of actually having the condition. For example, Katherine questioned her acquaintance's claims to be diabetic, commenting:

> How in the world can she be diabetic when she's not getting any tablets or anything like that?

As also observed in Lawton et al.'s (2008) earlier research, across the case studies tablets were also interpreted as an indication of disease progression. Interestingly this progression was sometimes also attributed to ageing. For example, Jack at Strathfinella commented: "when my age went up, they started me on metformin just in case". However, tablets generally did not carry the same connotations of severity as injecting insulin, and the DSN at Strathfinella neatly summarised why this might be the case:

> When you take tablets, you can kind of forget it's there because you can take tablets for anything. But, when you're doing injections, it makes diabetes very real and that's often the time when [patients] have to actually take on board this is a serious problem.

From the six patients interviewed who were using insulin, only one had started using this within the last year, Margaret. She described feeling as if "I'd let myself down", as if she had failed to control her condition and that insulin was a result of this. Moreover, she described feeling that she had lost control over her life since starting insulin:

> I felt as if I had no control at all because I had to take the injections at a certain time… I have to go to this clinic, I have to do this, I have to do that and it's just a case of, I don't have the choice. I feel as if my life has just been taken over by the diabetes.

Margaret's feelings of failure and loss of control have been widely recognised in previous research (Hunt et al., 1997; Polonsky and Jackson, 2004). It was also reflected by many other patients (both insulin treated and not) who described the distaste of injecting themselves and the concern over a loss of control or spontaneity in one's life was widespread. However, it is also interesting to note that Margaret includes having to attend clinics as part of this loss of control, as she went on to describe herself as "always in demand".

Physical changes

Most of the patients I interviewed described some physical experience of having diabetes; however, these were not all viewed as equally significant or disruptive. For example, I noted above that Joyce avoided 'hypos' but reflected that the thirst and tiredness she experienced as a consequence of high blood sugars "can't be that bad, or I wouldn't be able to work". Others were ambivalent about whether particular physical experiences were related to their diabetes or not. For example, David, who was in his 70s and had been diagnosed over twenty years ago, told me that his feet were always cold and he thought this was perhaps due to his diabetes, but he also commented that:

> With diabetes there's no physical evidence you're ill. If it hadn't have been… telt I'm diabetic, I wouldn't have ken any difference.

Having cold feet was not experienced as particularly disruptive by David and hence did not provide sufficient evidence of illness. Also along similar lines, elderly patients found physical indications of diabetes difficult to disentangle from other ailments which they attributed to old age. Carol was in her eighties and suffered from arthritis as well as diabetes. She explained that she was not sure whether the numbness in her hands was caused by her arthritis or her diabetes:

> It's difficult to separate my diabetes from my getting old and my sort of arthritic condition. I mean, it all makes up into me, as being me.

Both diabetes and arthritis were incorporated into Carol's perception of her ageing self. In Sanders et al.'s (2002) study of older people's experiences of osteoarthritis they demonstrated that, although the condition might have considerable consequences for people's ability to carry out every day tasks, arthritis was an anticipated part of old age and as such carried little significant meaning. Even though disruptive to daily activities, numbness in hands and feet were not always considered to carry any significant meaning as signs of poor blood glucose control or being at risk of further diabetic complications. As has been observed elsewhere (Corbin, 2003) unless a physical experience was disruptive to daily life and unexpected, it was generally not considered significant in terms of its consequences or its significance.

Summary

In this section I have very briefly outlined some of the factors from patients' wider lives and physical experience of living with diabetes which influenced their perceptions of the disease's progression and severity in all three case studies. As noted above, these factors have been identified and discussed elsewhere. However, these factors are significant to this research as they need to be borne in mind in the consideration of the influence of health service organisation on patients' perceptions of their disease's progression and severity. It is to this consideration which I turn in the next section.

Local constructions of professional expertise and the meanings of referrals

In this section I will argue that patients' perceptions of expertise can be informed by multiple factors drawn from the context of care organisation at each practice. I will also highlight the associated significance patients attributed to care organisation as an indicator of disease progression and severity in each case study.

Silvenea

At Silvenea referrals to a consultant diabetologist were a rare event and none of the patients interviewed told me that they had been referred to a diabetologist or the general medical consultant at Oldtown for diabetes care. A few patients had had consultations with the diabetes specialist nurse (DSN) at Oldtown hospital. However, she was generally not presented as having greater knowledge or expertise in diabetes than Dr Harrison, the GP. Joanna and Doris had both attended her clinic when they were first diagnosed and before they registered at Silvenea. Joanna in particular had found the DSN very helpful:

> She'd just tell me the new way of [self monitoring of blood glucose], and how to do it. And it was quite encouraging and then she said this is my number you call me if you ever need me, if you ever need to talk or anything.

The DSN was supportive and encouraging shortly after Joanna's diagnosis over 16 years ago, at a time when she said she had felt that "nobody cared". However, since she registered at Silvenea she no longer consulted the DSN and she had on Dr. Harrison's advice and reassurance reduced her self monitoring of blood glucose. The use of regular self monitoring of blood glucose, suggested by the DSN, was over-ruled by Dr Harrison, who told me that he viewed this procedure as unnecessary for patients with type 2 diabetes who were not using insulin.

Another example of patients' perceptions of the role of the DSN was given by Ian, who had attended her clinic, but, although referring to her by name, thought that the DSN was a dietician. The DSN was not presented by patients at Silvenea as having greater expertise in diabetes care than Dr Harrison, his advice was taken over hers and several appeared to assume her expertise was limited to dietary advice. This perception of expertise seems to be inter-linked with a more general trust in Dr Harrison, based on past experiences of competence and care which I discussed in the previous chapter.

The patients I interviewed at Silvenea generally thought that a referral to a consultant was unnecessary. Even those who were experiencing some early stages of diabetes complications did not suggest that they wanted to see a consultant. For example, as mentioned above, Carol and Frances described numbness in their hands and feet but neither suggested that they wanted to see a consultant or the local DSN. Although both Frances and Carol recognised that this numbness was due to their diabetes, and Carol told me that finding a blister, which she had not felt, on her foot had really "awoken" her to her diabetes; neither suggested that they interpreted this as a sign that their condition was serious enough to warrant a referral. This may be because they also interpreted the numbness as an anticipated part of old age, as discussed above. However, I would also suggest that these patients' trust in Dr Harrison to provide appropriate care contributed to their perception that their numbness was not a significant concern. For example, on a slightly different topic, I asked Carol if she had ever received advice about her diet and she responded:

> If Dr Harrison was worried about my diabetes, he would start to enquire about my diet.

She defers to Dr Harrison's judgement as to whether she needs advice and in assessing the state of her diabetes. Similarly, when I asked another patient, Doreen, if she had ever attended the diabetes clinic at Oldtown she responded that she did not think it was necessary:

> I would go by what my doctor said. If he thought it was necessary for me to go and see a diabetic consultant, then I would accept it as he obviously thinks I ought to, so I would just go, [but] I would be surprised because it doesn't really affect my life very much.

As in the case of the necessity of self monitoring of blood glucose, or receiving information about one's diet, Doreen deferred to Dr Harrison's judgement about the necessity of referrals. Hence, the significance of being referred to secondary care or not, which Lawton et al (2005) have shown can be interpreted as an indication of disease severity was mediated by the patients' "confidence" (Gregory), "faith" (Carol) or trust in

Dr Harrison to provide competent care. So, although in Doreen's comments above, she states that she would be surprised to be referred to a consultant because she described no physical experience of the condition and it did not disrupt her life, if Dr Harrison thought a referral was needed she would not question this. The only exception to the general deferment to Dr Harrison's judgement in referrals was Steven. As I noted above, Steven had researched his condition more than other patients on the island whom I had interviewed and commented that a referral for "specialist advice or treatment" would be necessary if "there were any complications".

At Silvenea the DSN was not perceived as having greater expertise than Dr. Harrison, perhaps because she was a nurse, or because she had not introduced any of the patients I interviewed to insulin. The perceptions of differing expertise of the professionals involved with diabetes care were related to the trust these patients had in Dr. Harrison and a lack of awareness that the DSN might have greater expertise in diabetes, as well as the absence of a local consultant diabetologist. Moreover, the perceptions of Dr Harrison's care and competence also informed an assumption that he would refer as and when it was considered necessary.

Corryhabbie

The patients at Corryhabbie generally viewed the hospital clinic as the seat of specialist knowledge. However, these patients also presented the organisation of their care in a slightly different way to those at the other two case studies, which, I will suggest, can be attributed to the continued regular involvement of the hospital clinic in their care.

As noted in the previous chapter, patients expressed a preference for receiving their diabetes care locally at Corryhabbie health centre, but viewed the hospital as having much greater expertise. For example, Bert commented that Vicki, the practice diabetes nurse, "usually just checks my blood pressure and so forth but any sort of control is usually done by [City hospital]". Vicki was viewed as competent at monitoring the condition, but key clinical decisions, in their view, remained the domain of the hospital.

However, in contrast to Lawton et al.'s (2005b) research, none of the patients I interviewed at Corryhabbie had had one location of care replaced with another and hence did not interpret the reorganisation of their care as an indication of the state of their condition. As Bert put it, attending the clinic at Corryhabbie was "an extra".

Only Kathleen was receiving practice only based care and she had never been referred to the secondary care clinic. Kathleen's perception of Vicki's expertise was presented in contrast to the GPs rather than the hospital and, as Vicki appeared to have greater specialist knowledge than her GPs, she saw no need to see a hospital consultant:

> I think this is good whereby you've got the diabetic clinic and the diabetic nurse because she's dealing with a lot of other diabetics and understands the problems, and it's much easier to talk to them [nurses]. I mean, you can't expect a doctor to have specialist areas all over the place… I've never seen a consultant and it's never bothered me that I haven't seen a consultant, cos I'm quite happy seeing Vicki because, you know, that's what she specialises in.

Kathleen's perception of Vicki's expertise was seemingly enhanced by the perception of Vicki specialising in diabetes care, rather than diabetes care being incorporated into everyday general practice. Like Kathleen, Susan also expressed confidence in Vicki's expertise:

> I got the option to either keep going to them [the hospital] while I started insulin or just to go to Vicki. I chose to go to Vicki because it's nearer and secondly because I feel I've got a really good rapport with her and I just find, she knows exactly what she's speaking about… I would quite happy nae ever go back into see the consultant in the City because I feel that everything I need I'm getting from Vicki.

Susan was particularly confident in Vicki's competence, perhaps partly because her personal rapport with her, but also perhaps because of her own knowledge of her own diabetes. In addition, Susan assumed that Vicki had the same level of training as the DSNs she worked with in hospital, commenting that:

> I think they're all actually trained together because they all know each other… as far as I'm aware, get the same training and they certainly all know each other cos they're all based at the City Hospital originally.

Hence, from Susan's perspective, Vicki's diabetes expertise was equivalent to that of the DSNs. Hence, she told me, she had felt happy not to receive frequent secondary care appointments for her insulin management.

Only Martha, as I discussed in the previous chapter, questioned Vicki's clinical knowledge and competence. Unlike the other patients I interviewed, she also told me that when she had first started to receive care at the practice she thought she would no longer be able to attend the hospital clinic. However, her consultant asked whether she "would you still like to continue to see" him. Unlike some of the newly diagnosed patients in Lawton et al.'s (2005) study, Martha did not interpret her partial discharge from secondary care as a sign of her disease improving or stabilising. Rather, as she perceived the change to be initiated by Vicki, who sent her the original letter inviting her to the Corryhabbie clinic, and came to judge Vicki as uncaring and incompetent, she assumed that the discharge was inappropriate. Hence, it was not interpreted as an external indicator of the state of her condition.

So at Corryhabbie, whilst the hospital was generally agreed to have greater expertise in diabetes care as a whole, Vicki was perceived by some as having almost an equivalent level of specialist knowledge. Moreover, as none of the patients had been completely discharged from the hospital clinic they did not interpret the reorganisation of their care as an external indicator of their disease. Finally, for Martha, who considered herself as only continuing to receive diabetes care in hospital because she had been able to request it, her near discharge was not interpreted as an indication of the state of her disease because it was initiated by Vicki, whom she did not trust.

Strathfinella

At Strathfinella, as at the other two practices, there was a general consensus that the hospital clinic was the centre of diabetes expertise. Like the patients at Silvenea, and in contrast to Corryhabbie, for most of the patients at Strathfinella who were not attending the Braeburn Hospital clinic, it was seen as somewhere where one would be referred if "you were having a lot of trouble with your diabetes" (Katherine). However, in contrast to the other two case studies, several patients at Strathfinella also suggested that a GP could have expertise equivalent to that of the consultants.

The recently retired GP, Dr. Ailis Sinclair, had been the diabetes lead at Strathfinella for nearly 20 years before Dr. Scott took on this role. Indeed, it was Dr. Sinclair who, I was told, had diagnosed most of the patients I interviewed. Jack and Catriona who had both been diagnosed by Dr. Sinclair outlined their views of her expertise:

> [I was] never seen at Braeburn because Dr Sinclair was doing Braeburn as well. She was always the expert and then she actually took over Braeburn before she retired. So she was just doing it here, ye know… [At this practice] they know the whole situation from day one. I'm quite confident here they know what they're doing. I'm no quite sure if Dr Scott is diabetic herself… I've got a funny feeling she is. I think that's why she studies it… I certainly know Dr Sinclair had it. (Jack)

> My first GP… was a specialist herself she specialised in it cos she had diabetes badly from the age of 7 or something… Ailis was really hot stuff. She had the same views as me, in the sense that you really have to look to see what's happening with this patient, is there any way we can add to these guidelines… and she ran the clinic at Braeburn. She was the first consultant there. (Catriona)

At Strathfinella the previous GP was perceived as a specialist in diabetes, with equivalent expertise to the hospital based consultants. This view was based on her having worked in the hospital based clinics for diabetes and the fact that she suffered from diabetes herself. This latter perception of expertise was founded on the clinician's personal experience of the condition rather than her professional knowledge. This notion

of expertise based on personal experience was returned to by several of the patients at Strathfinella.

In the quote above, Jack suggests that Dr. Scott was also likely to have diabetes and that was both why she was interested in it and why she had the specialist knowledge to act as GP lead for diabetes. Joyce, who had received care from Braeburn since diagnosis because she had to start insulin immediately, also partially attributed the expertise of the clinicians there to what she assumed was their personal experience of diabetes. Joyce commented that:

> Up in Braeburn they knew everything, you know, and down here they do know but it's not so. I don't know. Everybody up there was diabetic. Even my nurse up there was diabetic, so she knew you know, [things] the nurse down here didn't, she used to go on about mood swings and everything.

Joyce had been diagnosed since Dr. Sinclair retired and unlike the other patients she had been referred immediately to secondary care which, I would suggest, had strengthened her view that the secondary care clinic had much greater expertise than the practice. As I will discuss below, she went on to explain that their greater expertise in diabetes was not the only or main reason she wanted to return to the Braeburn clinic. However, what I would like to highlight here is that, just as the other patients assumed that professionals they perceived as experts in primary care had diabetes, Joyce assumed that the experts at Braeburn must have gained some of their knowledge from personal experience of having the condition.

Despite this, two patients at Strathfinella did express a desire to be referred to the Braeburn Hospital diabetes clinic. The first of these was Catriona who, since Dr Sinclair had retired, felt her care was no longer informed by clinicians with sufficient expertise:

> My practice [has] a clinic and they treat diabetes separately. But they've got a whole load of guidelines and I would suggest that many GPs rely on those guidelines rather more than I would ideally like to see.

The lack of clinical judgment, which Catriona considered to be evidenced by what she perceived as an overly heavy reliance on clinical guidelines, was interpreted as a lack of engagement with the condition resulting ultimately from a lack of knowledge and expertise. This combined with her distrust of the way in which the local system of health care operated as a whole supported her unmet desire to see a consultant diabetologist:

> If I could go, to, a consultant diabetician, I would, but I can't. Not here. Not in Scotland. Certainly not at Braeburn Hospital
> **Do you feel that you need to see a consultant ?**
> I think I may have now reached the stage where it would be helpful [rather than] just giving me another tablet… [But] I don't think [the DSN] would [see me]… cos, I'm in the practice, I go to a clinic, it's all there, it's all on the computer. I'm just another body and in that sense, I've never felt so frightened in my life…

Catriona was keen to see a consultant in order to take a more investigative approach to controlling her diabetes, but was constrained by the NHS system itself from taking the steps which she felt were necessary for her health. These concerns had arisen because she did not view her current GP to have the same level of expertise as Dr Sinclair. She did not think she could access specialists through the NHS because she was already receiving practice based care. Equally, she commented that she could not step outwith the NHS as there was no local provision of private care.

Expertise was constructed in a much more nuanced way by the patients at Strathfinella than a simple split of general practice as the site of generalist knowledge for monitoring the state of the condition and the consultant led clinic as the source of expert knowledge. The case of Dr. Sinclair suggests that patients did recognise individual clinicians as sources of specialist knowledge even when based in general practice. Moreover, expertise could stem from not only professional knowledge and credentials, but could be enhanced by the clinician's personal experience of living with a condition. Catriona's awareness of the use of clinical guidelines interestingly also suggests that over reliance on such guidelines can undermine perceptions of expertise. However, other patients did

not demonstrate an equivalent level of awareness of what informed clinical decision making and did not express similar desires for referral.

The other person at Strathfinella who told me she wanted to attend the clinic at Braeburn Hospital was Joyce, who as I explained above, had received care there from diagnosis but had recently been discharged, which she attributed to having missed an appointment. As outlined above, one of her reasons for wanting to return to the Braeburn clinic was her perception of the greater level of expertise of the professionals based there. I asked her whether she thought that Erica had the right amount of knowledge to deliver her diabetes care:

> She is very good at it. She knows what she's doing. Oh yeah, she knows. I mean, we've messed about my insulin quite a few times and it's worked. She has great ideas, things like that. But it's very annoying about the diabetic clinic, you know… it was very harsh [to be discharged without an explanation].

She thought that Erica was sufficiently competent but continued to want to be returned to the hospital; she went on to give another reason for this:

> [At Braeburn] my dietician was always the same and I always looked forward to going and seeing her cos we talked about everything and anything, you know… It was never a personal thing with the doctors up in the clinic but I always looked forward to going and seeing my dietician… I just got on so well with her… What if my diabetes were really, really bad? Are they going to refuse to see me? These are experts, these have specialized in diabetes these people. But never mind. It's just the dietician up there. I really liked her. She was lovely.

Joyce's comments suggest that it was the rapport she had with the dietician rather than the expertise of the consultants which was the primary reason for her wanting to return to Braeburn. In addition, she expresses anxiety that the clinic would not take her back if her diabetes became worse. It is these factors, rather than a perception that her diabetes is being poorly managed in general practice, that she suggests are the source of her wishes to return to secondary care.

In addition to the generally perceived difference in expertise between practice and hospital at Strathfinella (particularly since Dr Sinclair had retired), patients also perceived differing levels of expertise between the two professionals they saw for their diabetes in general practice: Erica and Dr Scott. As mentioned in the previous chapter, patients tended to view Erica as both caring and competent in carrying out the various monitoring tasks of their diabetes reviews. However, patients were also well aware that Erica discussed the results of their blood tests with Dr Scott and that they would be referred to her if any changes were thought to be necessary.

Erica was viewed as being "very good at it" (as Joyce phrased it) but ultimately the referral of patients to Dr Scott if they were having problems, and then on to secondary care if their diabetes was "really bad", suggests hierarchical layers of expertise and Erica was perceived to be at the bottom of these. This was interesting, since it was, in fact, Erica who had received specialist training in diabetes care.

Although Erica's knowledge was recognized and commented on, it was generally assumed by patients to be additional to, or slightly less than that of the GPs, rather than filling gaps in the doctor's knowledge. Jeremy was the only patient I interviewed who had joined the practice after the re-organisation of their diabetes clinic and hence had never met Dr. Scott or any of the GPs at the practice. He saw his diabetes care as being provided entirely by Erica:

> She's very good, she's all genned up on it, you know, which must be a good relief for the doctors at the health centre to get on with other things, you know… I find her very easy to talk to and she knows all aboot diabetes… if somebody's well versed up on something, it's nice to be able to talk to them because they know what you're talking aboot like, you know. Simple as that. I'm sure the doctors here know all about diabetes like. It's a very common thing now. (Jeremy)

Although Jeremy recognises Erica's competence and emphasises how much she seems to know, ultimately, Erica, perhaps because she is as a nurse, is still assumed to know less than the GPs. This perception was further enhanced by the organisation of care

itself. It was also the perceived differentiation in expertise within the practice (rather than between the practice and secondary care) that patients drew on as an external indicator of the state of their disease. For example Joyce commented that:

> Dr Scott is good, but if Dr Scott's not called me, I know everything's fine, you know.

Similarly Jonathan explained:

> I go and see Erica, she takes blood and if there's any problems Dr Scott gives me a kicking. (LAUGHTER)… The last time, I knew it was alright because after I'd been to see Erica, she said she'd write to me. If there's no change or anything, she sends you a little letter to say everything's alright… but if there's any problems, then she… talks to Dr Scott and then I get a call to see go and see Dr Scott. And most times, I don't get to see Dr Scott. I seem to be fairly stable.

As receiving a letter indicated that an appointment with Dr Scott, would not be necessary this was also interpreted as a sign that one's diabetes was stable. Most patients' perceptions of their professionals' expertise at Strathfinella were informed by both the stereotyped expectations of doctors and nurses (as implied by Jeremy's observations) and also the organisation of care itself. The fact that one was referred on to a GP when there were any difficulties created the perception that they knew more than the nurse. This in turn was interpreted as an indication of disease progression.

Changes in the frequency of appointments

Across all three case studies, and in addition to referrals between professionals, my interviews with patients indicated that changes in the frequency of review appointments could also be interpreted as an external indicator of the state of one's condition. Patients were asked to return for another review appointment as the health professionals considered clinically appropriate; so for example, a person might be asked to return every three, six, or twelve months. However, the way in which changes to the frequency of review were interpreted was mediated by patients' perceptions of the trustworthiness of the professional and the practice organising the review appointments. For example,

Jeremy who, as I showed above, felt that he was receiving competent care from Erica, pointed out that his review appointments had changed:

> They used to send [an appointment letter] every 6 months but because I'm keeping quite well, they put it doon to every year now.

Because Jeremy believed that he was receiving appropriate care he interpreted the change in the frequency of his appointments as an indication that his condition had improved. Rather than, for example suggesting that he had been lost in the system, or the practice was trying to reduce costs. His perception that a reduction in the frequency of appointments meant that his condition had stabilised may well have been supported by reassurances from his health professionals but he did not mention that.

Martha, who, as we have seen, was particularly sceptical of the competence and care provided by Vicki at Corryhabbie, had also experienced a few changes in the frequency of her appointments. The first was initiated by the hospital where she felt she "was seen whenever he (the consultant) thought I should be seen". So, when the consultant reduced her appointments from three months to six months and then to once a year, Martha interpreted this as an indication that her diabetes was "fine". However, in direct contrast, when the diabetes clinic at the practice failed to provide a review appointment in the month she was expecting it, she interpreted this as an indication that they were not "keeping an eye" on her diabetes. She complained that she was only being seen when "it suits" Vicki, which, she regarded as "not very satisfactory", and certainly not as an external indication that all was well with her diabetes.

Summary and conclusion

Patients' perceptions of the severity and progression of their diabetes are informed by multiple interwoven factors. This chapter has focused on how interpretations of three different organisations of diabetes care might add to patients' perceptions of their condition. It has already been noted that for newly diagnosed patients with type 2 diabetes "health service delivery could influence patients' disease perceptions, at the

same times as patients' disease perceptions could inform their… preferences for their future diabetes care" (Lawton et al. 2005, 1425). The above cross-case analysis adds to this by highlighting that the meanings patients attribute to health service organisation are related to their previous experiences of care and locally constructed conceptualisations of professional expertise. Hence, what this organisation might mean as an indicator of their condition, is also dependent on their past experience and local perceptions of professionals' expertise.

Perceptions of expertise partly followed traditional stereotypes of the GP as more expert than the nurse and the consultant as more expert than the GP (Lawton, 2009); however, they were also informed by other factors. For example, patients at Strathfinella, in particular, highlighted that perceptions of expertise were not limited to professional knowledge, but also included personal experience of living with diabetes. This particular perception of expertise was related to their past experiences of receiving care from Dr Sinclair who had diabetes herself. In addition, further information about clinicians, such as knowing that Dr Sinclair also worked at Braeburn, the seat of local diabetes knowledge, also furthered perceptions of her expertise in diabetes.

In addition, local patterns of referral informed patients' perceptions of expertise, as was again evidenced through the relationship between Erica and Dr Scott at Strathfinella. Dr Scott was assumed to be the more expert, partly because of traditional stereotypes, but also because patients knew they would be referred on to her if there was a 'problem'. Erica's lack of specialisation also furthered the stereotyped perception of the higher level of knowledge at the hospital clinic. In contrast, at Corryhabbie, Kathleen and Susan's perceptions of Vicki's expertise were enhanced by her specialisation in the condition, and the fact that they were referred to her by their GPs. However, Vicki's expertise was still perceived by most patients at Corryhabbie to be less than that of the hospital clinic, and perhaps more focused on monitoring than on making decisions regarding disease management. I have suggested that this was again not simply explained in terms of traditional stereotypes, but also the continued involvement of the

hospital and sometimes poor organisation of appointments at Corryhabbie, such that the hospital did seem to patients to still "be in charge". At Silvenea patients' perceptions of receiving competent care in general from Dr Harrison, extended to include his provision of diabetes care. Hence his advice over self monitoring of blood glucose was favoured over that of the DSN, whose professional knowledge patients seemed to remain unaware of. Experiences of care organisation within each practice, and in relation to secondary care, informed patients' perceptions of expertise, and hence what it meant to be referred from one professional to another varied across the cases. So, the significance of these referrals as an indicator of disease progression or severity also varied across the cases.

Patients' perceptions of competence and expertise also inter-linked with their trust in individual clinicians. For example, patients at Silvenea deferred to Dr Harrison's judgement on the necessity of referrals, which they may then have gone on to interpret as an indication of the state of their condition. Similarly, the meaning ascribed to changes in the frequency of care was related to trust in the clinician initiating those changes.

In Abbott's (1988) theory of the system of professions, already mentioned in chapter five, he suggests that public perceptions of the relative jurisdictions or expertise of professionals deal with archetypes and are quite stable because they treat each professional group as homogenous. This sits in contrast to the daily negotiation of "fuzzy" workplace jurisdictions experienced by the professionals (Abbott, 1988, 66); for example, in organising the delivery of diabetes care. However, Abbott (1988) argues that this contrast must go unnoticed by the public or it would lead to questioning of professional jurisdictions. My data suggests however, that the local negotiations of jurisdiction over diabetes care did not go unnoticed. Patients' perceptions of their primary care professionals' expertise in diabetes were related to the local organisations of care, personal knowledge of the experience of the individual professional involved, and trust in their competence and care. As stereotyped perceptions of expertise are blurred within the local context of care provision, so the meaning of being referred from

one professional to another as an indication of disease severity was also locally contingent.

In the next chapter I will discuss professionals' understandings of "patient empowerment" and patients' experiences and desire for involvement in clinical decisions. This provides a final example of how professionals' interpretations of one aspect of health policy can come to take differing forms in the local context of general practice, and how it may therefore differentially affect not only patients' experiences of their health care, but also their perceptions of their own role in managing their condition.

Chapter 8: Health professionals' and patients' perceptions of their roles in diabetes management

Introduction

In the previous chapter I showed that patients' perceptions of health professionals' expertise are partly informed by local organisations of care and patients' previous experiences of diabetes services. This chapter considers a possible relationship between how professionals interpret a particular aspect of health policy in relation to their understandings of their role and that of the patient in diabetes management, and patients' experiences and desire for involvement in their care.

Scottish health policy aims to improve patients' involvement in their own health care in three ways: patient involvement in the organisational design of health services, consulting patients about the quality of their health care and enabling patients to develop a "partnership" with their clinicians in "making decisions about the right treatment and care" (Scottish Executive, 2003, 18). The Scottish Diabetes Framework reflects all of these broad policy goals. In this chapter I discuss the Framework's approach to the last of these three, which it refers to as "patient empowerment" and explains in the following manner:

> Information and education enable people with diabetes… to make informed decisions about their diabetes and therefore become key partners of the health care team…People with diabetes need help to acquire the information, skills and confidence to mange their own care, with diabetes services there to provide help and support when needed. (Scottish Executive, 2002, 38)

The Framework's explanation of patient empowerment is informed by Diabetes UK (Scottish Executive, 2002, 38) and has two strands: firstly, patients will have the education, skills and understanding to manage their own diabetes, and secondly, patients will be involved in making decisions about their treatment and care. Patients are expected to be motivated to learn about their condition and active in making decisions

about its management. Integral to the notion of "empowerment" presented in the Scottish Diabetes Framework is the need to provide patients with education to make "informed choices" (Scottish Executive, 2002; 2006b).

Health policies assume that, once educated, patients will want to actively self-manage their diabetes and be involved in choosing regimens of self-care and treatments in consultation with their health professionals. Since the policy also aims to improve the patient's health it assumes that patients will make choices reflecting biomedical goals; after all, it is highly unlikely that anyone would choose to allow the complications of diabetes to develop. Hence, policy assumes that patients' choices will, for example, mean that they will try to maintain blood glucose control. The professional role is presented as being to "support" patients' in making "informed decisions" whilst also supporting them to reduce the "risk of long-term complications" through regular surveillance of risk factors and the provision of treatments (Scottish Executive, 2002, 36). Policy does not suggest that these two expectations might ever be contradictory because it assumes that, once informed, patients will make the 'right' choice.

However, assuming that a patient's self-care will be furthered through education without taking into account their social, cultural and economic circumstances is problematic, as has been repeatedly observed (Bissell et al., 2004; Drummond and Mason, 1990; Hunt and Arar, 2001; Hunt et al., 1998; Parry et al., 2005; Schoenberg et al., 1998; Schoenberg et al., 2005). Rather than repeating these well known arguments, this chapter will outline the local provision of patient education and consider both professionals' understandings of the policy goal of "patient empowerment" (Scottish Executive, 2002) and patients' experiences and desire for the education and involvement in clinical decisions. By considering the professionals' espoused approaches to patient involvement in clinical decisions alongside patients' accounts of their experiences and their preferences for involvement, I will suggest that there is a possible relationship between these.

Local organisation of patient education in type 2 diabetes

NHS Clinical Standards for Diabetes (Clinical Standards Board for Scotland, 2002) require each Health Board to provide structured multidisciplinary programmes of education for all people with diabetes. For example, programmes such as Diabetes Education and Self Management for Ongoing and Newly Diagnosed (DESMOND) are recommended for people with type 2 diabetes by the Diabetes Action Plan (Scottish Executive, 2006b) and the 2005 review of SIGN guideline 55 (Scottish Intercollegiate Guidelines Network, 2005). Yet, the extent to which structured programmes were actually being provided at the time of my research varied between Health Boards (NHS Quality Improvement Scotland, 2007a; 2007b; 2007c). In addition to these programs, each of the MCN guidelines used by the case studies contains a checklist of initial education topics to be discussed with newly diagnosed patients on an individual basis. These guidelines do not vary in the broad topics they cover. However, I found that the organisation of structured education for type 2 diabetes varied between the differing Health Boards, within which my case studies were based, and even between the Community Health Partnership (CHP) areas within these.

The approaches to patient education adopted at a Health Board level obviously influenced what education programmes were on offer at each case study. At Corryhabbie, the programme of structured education was directed at newly diagnosed patients and had not been experienced by the patients interviewed in this study. At Strathfinella, most of the patients I interviewed had been diagnosed by Dr. Sinclair and they told me she had taught them about what diabetes was. A new "Staywell" (Intouch with Health Ltd, 2008) education programme was also introduced whilst I was carrying out my fieldwork at Strathfinella, which was going to be offered to all the patients with diabetes at the practice in the future but had not yet been received by the patients I interviewed. Finally, at Silvenea there was no structured education programme, but information was provided on a one-to-one basis as requested by patients or deemed necessary by the health professionals.

As a result, although some patients (three out of 23 interviewed) had sought information sources, such as Diabetes UK, in all three case studies the education which the patients I interviewed had received was provided by the individual healthcare practitioners they had interacted with. As I will now discuss, the way education and involvement was approached by these differing professionals varied alongside their differing conceptualisations of the meaning of "patient empowerment".

"Empowerment": the professionals' perspective.

In this section I will outline three overlapping understandings of "patient empowerment" espoused by the health professionals, these included: empowerment is education; empowerment is patient choice; and empowerment is impossible and undesirable. As I will now discuss, the prevalence of these understandings, varied both across case study general practices, and between doctors and nurses in ways which reflected the organisation of responsibility in diabetes care. I will outline each of these understandings of 'patient empowerment' in turn and then reflect on how they related to professionals' perceptions of their role and responsibilities in facilitating involvement in diabetes care and those of the patient.

Empowerment is education

> Patient empowerment is when [a patient] can control their diabetes and take on board all the complications… Education, education, education, education. [That is] my role and the practice nurses and the GPs.

This quote from Kiera, the DSN for Silvenea illustrates the understanding that "education equals empowerment", as Vicki at Corryhabbie put it. This approach was particularly emphasised by these two nurses who specialised in diabetes care, but education was also presented as a pre-requisite to the second understanding of empowerment as choice which I will present below.

Understanding education as empowerment is about being able to control one's diabetes through a biomedical understanding of the condition and what practices of self-care are

expected to help 'control' it. The patient is empowered in relation to their condition rather than in relation to the professional. They manage their diabetes but may not necessarily be involved in clinical decisions or even in deciding what information is relevant to those decisions. The health professionals' role is to provide the necessary education, the patients' role is to learn and understand and ultimately act on this knowledge. Vicki, expanded further on this approach:

> The more they [patients] know, the better they will do. [In the past] You did what you were told, you didn't question anything because you didn't understand it… but it's so important that you understand… I think the key thing is; [knowing] why are you doing this? They come in [to a consultation]:
> "How are you"
> "Fine".
> "Ah, but you're not fine because I can see by your [blood] results, you're not fine"…and I just try to explain it all to them.

Education and knowing about diabetes is reached in two ways in Vicki's description. Firstly, she comments on how patients should question in order to understand. In this approach the patient is taking the initiative to learn about their condition. In contrast, Vicki then goes on to describe how a patient might come in and claim to be "fine", but she places more value on their blood test results as an indication of their health than their subjective assessment. Hence, Vicki aims to 'correct' their perspective of being "fine" to one which fits with biomedical indicators. In this second presentation of empowerment, it is Vicki, not the patient, who initiates the education, over-ruling and re-educating the patient's perception of themselves as "fine". Rather than a dialogue, the presentation of education here is as a one way flow of information directed towards the patient. The patient may be more empowered in relation to their condition but not necessarily through tailoring their self-care to their social circumstances.

When consulting with patients, Vicki and Kiera's approach may have been more inclusive than that explicitly presented in interview, but without observation of their consultations it is not possible to comment on this. Nonetheless, the understanding they presented in interview seems equivalent to using education to promote compliance with

biomedical regimens of self-care. Their approach to empowerment is to adopt the role of one of "educator" and "salesman", to borrow Lutfey's (2005) terminology. The goal of teaching patients about diabetes is to convince them of the saliency of biomedical understandings until they comply with biomedical models of self-care. Education achieves empowerment when patients accept and act in accordance with biomedical regimens of self-care.

A similar emphasis on education to promote self-care, and hence the patient's biomedical control over their condition, was common to the DSNs in all three cases and practice and district nurses at both Silvenea and Corryhabbie. For example, although Jenny, the practice nurse at Silvenea, was not directly involved in diabetes care there, she ran a diabetes clinic at another practice and commented that professionals should aim to "teach" and "gradually change the habits" of both newly diagnosed and established patients with diabetes. Similarly, Susie the district nurse at Silvenea talked about promoting self-monitoring of blood glucose as a way of educating patients with poor glycaemic control. The DSN at Strathfinella discussed the importance of providing patients with information and aiming to promote behaviour change. However, while nurses at both Corryhabbie and Silvenea emphasised educating patients, Erica at Strathfinella placed a slightly different emphasis in her description of her role:

> My role first of all, is to just assess how [patients] are generally… if they're newly diagnosed, to find out how they're adapting and adjusting to diagnosis, and I see that as the primary thing that I check and thus the patient has the opportunity to talk about. And, secondly, my role is to monitor [the condition] and to ensure that, patients are informed about their treatments, why they're on treatments, why we're doing the checks that we're doing… it is about living with a chronic disease and so from the studies that I had done and the work that I did… as a palliative care nurse, I can see [similar] threads… living with diabetes… is about change, it's about, in some situations, loss of certain aspects of their life, which just takes adaptation and relearning and support.

Erica's description of "informing" patients, is similar but not equivalent to educating patients until they agree with the biomedical model. In the quote above, drawing on her

experience in palliative care she emphasises "support" rather than education. This approach was possibly further enabled because, at Strathfinella, patients who were not meeting biomedical targets or who Erica perceived as non-compliant, were referred on to a GP:

> If I know I'm not going to change [the patients] behaviour in terms of their compliance then… I'll get them to see Dr Scott and often GPs get away with being much, much more direct, you know, directing with patients. Whereas, as a nurse, I just don't think it works at all, you know, we have to work with, what the patients will accept.

Erica was the only nurse who saw patients and then referred them to a GP if they were not complying, and it was this option to refer which seems to have enabled her to emphasise support and working with the patients more than educating them in the biomedical model. The second approach to empowerment built on patient education to suggest that empowerment was about patient choice, and in particular their choice to comply with regimens of treatment or not.

Empowerment is patient choice

When education failed to promote changes in the biomedical control of a patient's condition this was also explained by some health professionals in terms of patient empowerment as choice. As Kiera, the DSN at Silvenea, put it, "some patients don't want to look after themselves". This approach assumed that patients had made the conscious decision not to follow medical recommendations and this in itself was an "empowered" choice. For example, Susie, a district nurse at Silvenea, commented:

> You can give patients all the advice and information and teaching and implements to do stuff [e.g. blood glucose monitors] but at the end of the day, it's still down to them. If they don't take the medication… or if they refuse to follow a diet, you know… It's patient choice.

In addition, whilst, diabetes was recognised as a progressive disease, progression was more often associated with patients' failing to follow regimens of self care, as is

reflected in the following quote taken from a chronic disease nurse at Corryhabbie who cared for patients with both type 2 diabetes and coronary heart disease:

> If their HbA_{1c} is up, it's usually due to, well, not always because diabetes is progressive, but a lot of the time… their weight has increased or they obviously have nae been sticking to their diet, they haven't been exercising.

When education failed to change self-care behaviours, or bring HbA_{1c} measurements to the prescribed level, this was sometimes strategically presented as the patient's (morally dubious) choice. As Salmon and Hall (2003) have argued, the "discourse of patient control and empowerment served to free clinicians from responsibility for suffering for which they think that they can do nothing" (Salmon and Hall, 2003, 1976). Professionals did not need explicitly acknowledge that diabetes is not a disease which medicine can cure or completely prevent from progressing, and hence they were unlikely to be completely successful in its treatment.

However, the position that empowerment is equivalent to allowing patients to choose not to follow medical advice was not accepted in quite those simple terms by most of the health professionals across all three case studies. As in the quote above, these professionals recognised the progressive nature of diabetes and struggled with the idea of placing the responsibility for disease control solely onto the patient. They felt themselves to have a responsibility to ensure the continued health of the patient and that the patient was making an informed decision; for example Dr Scott commented that:

> If patients choose not to take exercise or change the diet, well that's not my fault as long as we feel that we have given the opportunity [for education] and that those who don't take the education in one format well, you try and shift it to work with them, and suit their lifestyle and these sorts of things... but I feel that I have to be sure, sure and double sure that we've tried every opportunity.

Even when the patient did seem to be making an informed decision, many professionals continued to view their role as to try and limit the progression of the disease. This created a dilemma of knowing when one should leave care to patient choice and when

one should act- a dilemma which differing professionals resolved in differing ways that I will go on to discuss further. However, I will first outline one final approach to empowerment which was espoused by Dr Harrison at Silvenea.

Empowerment is impossible

As I showed above, the nurses at Silvenea tended to express the view that the professional's role was to educate patients and that this would enable them to become better at managing their diabetes, and hence empowered. However, unlike the nurses, Dr Harrison was explicit that he did not consider 'empowerment' to be a genuine possibility:

> How can you empower patients? To empower patients [you] give them knowledge but unless you can interpret that knowledge, it's not power at all. All it is, is lies and deceit and I think it's much better that you form a trusting relationship with someone who tries to explain things to you as best they can and that's how I empower patients is by telling them what I think... all the information that I give is interpreted over the course of 20 years of professional experience.

In addition, he told me that he closely censored any information leaflets he put in the waiting room for pharmaceutical company bias. Similarly, he saw the prescription of monitors for self monitoring of blood glucose as unnecessary and "a classic case of drug company influence… I mean, type 2 diabetes not on insulin with a reasonable HbA_{1c} do not need blood glucose monitoring". Dr Harrison's approach to empowerment is underpinned by a particular understanding of the roles of patient and clinician which represents a division between lay and expert in a manner which echoes a Parsonian model of medicine (Parsons, 1951). He suggests that, instead of empowerment and information, patients are better having a "trusting relationship". However, the form of relationship implied seems to be one more of dependency than trust because it is not based on the sharing of clinical knowledge. In chapter six, I argued that patients at Silvenea did have high levels of trust in Dr Harrison. This was based on assessments of him personally and previous experiences of competence, rather than trust based on

sharing information about their condition. He also did not generally think that patients should spend time researching their condition or joining patient support groups:

> What a waste of time… shouldn't these people instead of going to a Diabetic UK group meeting, shouldn't they really be better going for a walk… you've no control over these groups. They may be a good thing, they may not… why get so focused on your diabetes?… Get a life.

He seemed to want to control the information patients received about their condition. Although Dr Harrison gave the example of one patient with whom he shared and discussed medical research papers in relation to his medications, he commented that:

> The bottom line of it all is that at the end of the day I say, here's what so and so think, this is what I think and he has always been relatively happy with what I think.

Even where there was a discussion of information, Dr Harrison seemed to expect patients to agree with his decision, hence he, rather than the patient, took the weight of responsibility for disease management. This, he thought, was the appropriate role of a doctor and hence he did not try and enable patient empowerment.

A dilemma

Each of the three conceptualisations of patient empowerment above can be understood as dealing with a moral dilemma in defining patients' and professionals' responsibilities in disease management. This dilemma was articulated more explicitly by GPs than nurses across the case studies. How professionals dealt with it varied, as Dr. Shore explained:

> Professional responsibility generally I think is to explain and inform in as clear a way as possible and provide options… but at the end of the day… if they say, I'm not going to do any more treatment, or look after it any better… we kind of have to accept that. I think, it's an individual thing as to how far you take it before you accept that, and some people will hammer away [trying to persuade or educate] and some people will stop earlier.

That treatment is viewed as the patient's choice once professionals have provided the necessary information reflects the health policy approach to empowerment in which professionals "support individuals to make informed choices" (Scottish Executive, 2002). However, Dr Shore recognises that the extent to which professionals try to influence this choice varies and my data reflects this observation. For example, Dr Andrews at Corryhabbie outlined how she would resolve the dilemma patient choice posed:

> If a patient comes up and says I want to stop [a medication] you can say well, that's fine – stop it now but your diabetes is going to go all out of control and we'll need to sort that out at a later stage… It will be an element of the patient making their own decision but you've got to guide them.

Whilst providing all the information and supposedly providing the patient with a choice, the professional aims to guide, persuade and generally influence that choice. Vicki's emphasis on education outlined above can be understood as another way of dealing with this dilemma by trying to persuade the patient into the biomedical perspective and hence to manage their disease. Overcoming the dilemma posed by patient choice by trying to convince or persuade patients was also evident at Strathfinella, but was undertaken by the GP not the practice nurse. At Strathfinella, I have already noted that Erica would refer non-compliant patients to Dr Scott because she could be more "directing with patients". Dr Scott also commented that her role as the "bad cop" enabled Erica to carry on being the "supportive one". Similarly, if a patient wanted to change their medication, Erica commented that "they have to speak to the doctor about choosing not to be on it, but we'll respect that". However, as at Corryhabbie, allowing patients a choice over treatments, or to reject treatments, was presented as problematic. Knowing how much education was needed and whether the patient was then able to make an informed clinical decision was difficult, and hence professionals at Corryhabbie and Strathfinella felt the need to "guide" and "direct" patient choice. Dr Scott explained why it was so difficult to hand over clinical decisions to patients and the dilemma created by the view of "empowerment" as patient choice:

> Ultimately the patients who choose to just blank information, it's their responsibility … [but] this is a very black and white picture … if [a patient] walks in and they say, 'I've had a heart attack and… the hospital said that this is probably because of my diabetes, if I'd known it was that serious, I would have, done something.' I will feel guilty. I will think I have failed, I should have made sure they knew how important it was.

Dr. Scott went on to explain further that, in some cases, she felt patient empowerment, and choice, happens "nicely", and that when it did it involved an "exchange of information" between patient and professional so that they worked as a "team". However, she felt difficulties arose with those patients who could not decide what they wanted and did not take responsibility for their decisions. She did not view "patient empowerment" and choice as releasing her from her responsibility for the patient's health. She also described her frustration with those patients whom she had provided all the information that she thought was relevant but who still could not decide, who repeatedly changed their minds, and who might then hold her responsible when they fell ill:

> And that's when you feel like removing all power from the patients and saying, I'll just tell you what you take and I'll be protected [from litigation] then.

Dr Scott was tempted to return to an entirely paternalistic role because she could never know whether the patient was making a truly informed decision and Erica's presentation of using her to "direct" patients suggests that she did seem do this.

At Corryhabbie Dr. Andrews dealt with the dilemma created by professional interpretations of 'patient empowerment' as patient choice by 'guiding' patients towards the 'correct' choice. Taking this 'guidance' to even greater extent, or perhaps more honestly admitting that he was not going to give patients a choice from the outset, Dr Harrison at Silvenea as shown above, adopted an overtly paternalistic approach. He did not offer patient choice because, ultimately, he felt it was his role and responsibility to draw on his greater biomedical knowledge to determine treatment regimens. Also, by rejecting the notion of patient empowerment, Dr Harrison sidestepped the dilemma

faced by the other clinicians of even trying to balance the "contradictory aims of active involvement with clients in disease management juxtaposed upon passive compliance with the advice and recommendations of the professional" (Thorne et al., 2000, 309).

At all three practices, GPs and nurses assumed that patient empowerment means educating or convincing patients of the biomedical understanding of diabetes so that they can choose a course of action. This assumption forms the crux of their dilemma; the patient is unlikely to have as much biomedical knowledge as the professional to inform their decision. Hence, a situation arises like those observed in Mol's (2008) ethnography of a hospital diabetes clinic, where "patient choice" appeared to be at odds with "good care". Unlike choice, Mol suggests "good care" would involve a negotiation between biomedical knowledge of the professional and incorporating diabetes management into the lives of the patients (Mol, 2008). My data suggests professionals have not yet adopted an understanding of empowerment as negotiation.

Notably in the approaches to patient empowerment above most of the professionals seemed to under-emphasise the patients' knowledge of living with diabetes and incorporating regimens of self-care into their lives in favour of educating the patient in biomedical knowledge. The exception to this was Erica, who, although she claimed to emphasise support and patients' concerns in her consultations, referred patients on to be 'directed' by the GP when they were not meeting biomedical goals or appeared to not be adhering to treatment regimens. Professional conceptualisations of 'empowerment' seem to draw on an implicit hierarchy of knowledge where clinical decisions are based on biomedical knowledge and, hence, empowerment means learning that knowledge. The professionals' conflation of 'empowerment' with education and biomedical knowledge leaves only two possibilities open: to either to persuade and educate in order to promote compliance, or to disallow involvement in clinical decisions and return to a paternalistic approach.

Discussion of the professionals' approaches

The themes of education and choice in professional approaches to 'empowerment' cut across the cases but the specific approaches to educating and involving patients were associated with individual clinicians or organisations of care, and as such were case specific. For example, I have suggested that at both Silvenea and Corryhabbie nurses tended to emphasise education and patient choice as the keys to empowerment. However, at Silvenea, patients consulted with Dr Harrison for their diabetes, who rejected the notion of education and involvement. So, based on the professionals' espoused understandings and approaches to empowerment and education, one would expect patients at Corryhabbie to have received more education or information than at Silvenea. At Strathfinella, where patients first consulted with Erica the practice nurse, one might expect patients to report being informed of clinical decisions and being able to discuss concerns but not necessarily receiving education to the same extent as at Corryhabbie. The professionals directly involved in clinical decisions, namely Vicki, Dr Harrison and Dr Scott, each resorted to some form of paternalistic guidance or persuasion across the cases. However, from their accounts, it is unclear how and to what extent professionals at Corryhabbie and Strathfinella offered patient involvement or choice before resorting to 'directing' or 'guiding' the patient. From Dr Harrison's account one would not expect patients to have been offered any explicit choices or further information unless they took the initiative to pursue these.

I will turn to outline and analyse patients' accounts of their education and involvement in clinical decisions regarding their diabetes and their expressed preferences for further involvement in making clinical decisions and/or receiving more information or education.

Being "empowered": patients' accounts and preferences for education and involvement

Professional presentations of 'patient empowerment', like that of policy outlined in the introduction to this chapter, include a concern with providing education about the condition and potentially involving patients in clinical decisions. In this section I will present and discuss patients' accounts of receiving education and information about their diabetes and the tests undertaken as part of their annual review, and being involved in clinical decisions about their disease management regimen. As my analysis indicated that patients' experiences and preferences for education and involvement varied by case-study, I will present the experiences of patients in each case study in turn. I will offer a possible explanation for patients' preferences for involvement in clinical decisions within each case and across the case studies, and consider alternative explanations.

Previous research has suggested that patients' desire to be involved in clinical decisions varies not only with demographic factors such as, age, sex, education and socio-economic status, but also, with experience of illness over time, the perceived severity of the illness, experience of symptoms, and the type of decision being made (Say et al., 2006; Thompson, 2007). Some studies have also noted that patients were more likely to want involvement in making clinical decisions when they perceived their clinicians as encouraging them to be involved (Adams et al., 2001; Blanchard et al., 1988; Sainio et al., 2001). In addition, in a structured interview study of patients' preferences for consulting style in general practice, McKinstry (2000) observed that patients tend to prefer the level of participation facilitated by their 'own' GP. However, McKinstry (2000) was not able to demonstrate whether patients simply preferred a consulting style which was familiar to them or actively chose GPs who consulted in their preferred style. Nevertheless, research by Porter et al. (1984) into patients' preferences for medical examination in pregnancy suggested patients do tend to prefer the style of care they know until they have experience of an alternative. Finally, it should also be borne in mind that "involvement" can mean multiple things (Entwistle and Watt, 2006), and

entail differing extents of information sharing and sharing of decisions (Thompson, 2007). For example, whilst receiving information about diabetes and the state of one's condition might be perceived as sufficient involvement for some patients, others might want to be involved in making clinical decisions, or even to make them without the involvement of their health professional (Thompson, 2007).

Silvenea

Six of the eight patients who I interviewed at Silvenea had been diagnosed there and described receiving an information leaflet on diabetes and diet when they were diagnosed. Doreen described this leaflet, which she had received from the practice six years ago when she was diagnosed:

> It was all about diet and what diabetes is and what you should eat and drink… but I said, this is my lifestyle, this is the sort of thing I do automatically.

Because the pamphlet gave general advice rather than being tailored particularly to her, she perceived it to be of little use except as reassurance that she already had the right diet. Doreen had also read an entry about diabetes in a medical encyclopaedia, but had not pursued any further information and was not interesting in knowing more. She described her condition as "borderline" and stated that she was "very obedient" with her medication. Doreen was not alone in paying little attention to these pamphlets and expressing no desire for more information or education about the disease. Ian and Gregory summed up the general attitude towards the leaflets amongst most patients at the practice:

> Well, it's years ago since I read it but… once I read it, I forgot about it. (Ian)

> Somewhere or other I've read a pamphlet or two about it, but I didn't really take a great deal of notice of it, to be strictly honest, because I didn't feel as though there was anything wrong. (Gregory)

Gregory was in his late seventies and Ian in his sixties and neither had experienced any complications or symptoms of their diabetes which they considered significant. They

had not taken a particular interest in the information when they were diagnosed over five years ago and had not pursued any further information, partly because they did not experience any physical effects of the disease. These patients did not perceive their diabetes as particularly severe and did not experience physical 'symptoms'. When I directly asked in the interview whether they were interested in being involved in treatment decisions, or whether they would like more information about their condition, (for example, whether they would like to know their blood test results) most patients said they did not feel any need for this. As Carol put it, they were content to take Dr Harrison's "word and just go by what he says".

Similarly, Joanna who, as I mentioned in the previous chapters, no longer self-monitored her blood glucose because Dr Harrison assured her that she was "alright", expressed no desire in being involved in clinical decisions or to know the results of the blood tests taken in her review appointment because:

> I just come and see [Dr. Harrison] and I know if there was anything wrong that he would tell me. So, I just leave it to him.

In Paterson et al.'s (1998) review of the literature on patients' experiences of living with diabetes they observe that over time patients gain expertise in managing their own diabetes by learning to pay attention to their own bodies and adapting their practices of self-care to fit with their everyday lives. However, my data suggests that this expertise in day to day practices of self-care does not always translate into a desire to be involved in clinical decisions. Joanna, who had had diabetes for nineteen years described learning about her diabetes through "trial and error" and said she felt that she felt confident in her daily practices of self-care to manage her condition, but, like most of the patients at Silvenea, she did not desire any involvement in clinical decisions with her GP.

None of the patients I spoke to at Silvenea described experiences of being involved in clinical decisions in consultations with Dr Harrison, or receiving information about their

blood test results unless they explicitly asked. Frances' account of her diabetes review exemplifies this:

> You go and he [Dr. Harrison] gives you yet more pills if he thinks you need them. So you carry on taking your pills.
> **HM: Do you see your results?**
> Well no. He talks to you. Well yes if you want to know. But there is nothing I can do about it though is there really? Even if I do know. Except worry about it perhaps.

Frances does not describe being informed about the measurements used to assess her condition or involved in making decisions about her care, but she also claims that she does not "want to know". This lack of interest, and willingness to rely on Dr Harrison's judgement, was expressed by seven of the eight patients interviewed at Silvenea and included patients who had been diagnosed within the past ten years and those who had had the condition much longer. The disinterested attitude towards being involved in clinical decisions at Silvenea also included patients who were experiencing some complications of the condition. For example, Frances and Carol who had numbness in their hands and feet. Another example was Doris, who had been diagnosed over thirty years earlier and told me that she was losing her eyesight and had recurrent ulcers on her legs which she ascribed to her diabetes. She continued to be quite deferent to the judgement and advice of her doctor, rather than wanting any further information or involvement. She commented that:

> As long as I keep doing what… the medical people tell me, I feel OK. If I'm told what to do that's what I've got to do.

She went on to tell me that she had only found out that one of the tablets she was taking was for her diabetes the week before our interview and had stopped using the blood glucose monitor she had been given at a previous practice five or six years ago when she moved to Silvenea and had damaged her monitor. She explained that she was not concerned about replacing the monitor because the health professionals "haven't said anything to me… they're taking blood out my arm. They do it regular." Because the professionals had not suggested it, Doris assumed that it was now unnecessary to

monitor her own blood. Similarly, all but one of the other patients at Silvenea were not interested in monitoring their own blood glucose levels, unless Dr Harrison advised them to. For example Doreen, who had never previously monitored her own blood glucose commented that:

> I would do if it was suggested that I ought to do it, fine, but I'd rather not prick myself.

The only exception to the disinterest in involvement in clinical decisions expressed by the patients at Silvenea was expressed by Steven, whom I mentioned in previous chapters had joined Diabetes UK and researched his condition on the internet. He questioned whether his HbA_{1c} test was carried out frequently enough and he commented that he would like "some kind of clearer explanation of exactly what the [annual] blood tests mean". He wanted more information and involvement in managing his diabetes. Steven was the only patient at Silvenea who expressed a desire to have "some way of self testing", such as a monitor to test his own blood glucose levels.

Steven, the only patient to express a desire for more involvement was also the only patient I interviewed at Silvenea who was under sixty years old, and the only patient at Silvenea who perceived his condition as "severe". These offer possible explanations for his greater interest in involvement in clinical decisions. However, other factors did not seem to relate to the variation amongst the patients at Silvenea. Six out of the eight patients had been diagnosed less than ten years earlier, but the two patients who had had diabetes nineteen years or more expressed no greater desire for involvement than those diagnosed in the past ten years (with the exception of Steven). As noted above there was also no difference to be noted between patients experiencing 'symptoms' or complications of diabetes and those not.

Whilst the variation in age and perceived severity of diabetes offers one explanation for the variation amongst the patients at Silvenea, it is notable that patients' preferences for involvement in clinical decisions are congruent with Dr Harrison's rejection of the

notion of patient involvement and emphasis on establishing a "trusting relationship" with a clinician who explains and tells you what he thinks you should do. Moreover, the seven patients who expressed no interest in knowing more or being more involved in making decisions about their care, were the same seven patients who I showed trusted Dr Harrison to be caring and competent in chapter six.

The GP's espoused understanding and approach to "patient empowerment", and patients' trust in that GP are also possible explanations for patients' lack of interest in being involved in clinical decisions at Silvenea. This is congruent with previous research which has argued that patients tend to prefer the style of healthcare they are accustomed to (Porter et al., 1984), and that some patients with a lot of trust in their health professionals may not feel the need for involvement (Thorne, 1993; Thompson, 2007). However, this tentative hypothesis needs to be considered further through a comparison with the other two case studies.

Corryhabbie

All eight of the patients interviewed at Corryhabbie now received their diabetes care from Vicki but their past experiences of diabetes care and involvement in clinical decisions varied much more than the eight patients interviewed at Silvenea. None of the patients had attended the local diabetes education group or any other structured education program but described receiving information from individual clinicians and from friends and family who were health professionals or had the disease themselves. Thomas, who was in his fifties and diagnosed less than ten years ago, commented that the GP "explained to me what it was and that was good enough for me". He had not been interested in knowing more. Only two patients, Kathleen and Susan, described seeking out more information at Corryhabbie. Even the three patients I interviewed who had had the condition for over thirty years also did not describe ever trying to find out more about it than had been offered in their initial explanation from a health professional. For example, Bert, who was in his eighties and had had diabetes for over forty years, commented:

> It's never something I've felt the need to dig into and get more information. I've always been quite content to accept the recommendations of the people I'm seeing… I suppose you could say it's a lack of interest.

Two out of three of these patients, Bert and Daisy, also did not express any interest in being more involved in clinical decisions. For Bert this may be partly attributed to the fact that he was receiving frequent appointments at the hospital to stabilise his increasingly frequent episodes of hypoglycaemia. For Daisy it might be attributed to her perception of her diabetes as "borderline" and not a serious concern, she even suggested that she may not still have diabetes, and commented that she thought Vicki "makes much more of a fuss of it than me".

These patients' lack of interest in involvement might be partly attributed to their long experience of having a passive role in clinical decisions in their past experiences at the hospital clinic. None of the patients I interviewed described being included in treatment decisions at the hospital clinic. Interactions with the hospital were presented by patients as what Thomas described as a "do what you're told exercise". On one level this was generally accepted by the patients who had long received their care there, as is exemplified by the quote from Bert above. However, others, such as George and Thomas preferred more involvement in clinical decisions, which was something they had experienced in their care from Vicki.

Four of the eight patients interviewed (Thomas, Kathleen, George and Susan) enthusiastically described Vicki's approach as inclusive; for example, Kathleen described her usual diabetes review appointment with Vicki:

> We talk about my general health basically… and then I get the opportunity to ask her about anything I want to ask her about … [and] … when I go in, she has already… got a list up on the computer from my file of the results of my blood test, so she can… tell me because I like to know what my blood sugar is, what my this is and what that is.

Kathleen had learnt about diabetes from a friend who was a health professional in Australia. However, this interest and involvement was encouraged and facilitated by

Vicki sharing information with her. Kathleen went on to tell me that Vicki had even taken some recipes from the low glycaemic index diet she had discovered to give to other patients, demonstrating the reciprocity she felt in her relationship with Vicki. Similarly, George, who was over eighty and had had diabetes for more than forty years, had established a good rapport with Vicki and commented that he felt she realised that he was "quite capable of looking after [his] own health" and "often mentions that 'you know more about it than I do'". Not only did Vicki share information about the condition and encourage the involvement of these patients through a two way sharing of information, she also offered patients choice in their approach to managing their condition. For example, Susan described Vicki giving her the option to increase her metformin dose or to start using background insulin. Similarly, Thomas told me:

> Vicki involves you… when I got this blood [glucose] measuring device, she said, you can either have that or have pills… So… we had a talk about it and I said, well, yeah, alright, I'll give the blood measuring thing a go.

While Thomas had been previously uninterested in finding out more about his diabetes, he did value being given the option over approaches to best managing it. Again, those patients at Corryhabbie who described being involved by Vicki were the same patients I showed in chapter six to consider Vicki both caring and competent and trusted her.

Previous research has observed that in some instances trust has been related to a limited desire for involvement (as at Silvenea), in others it is related to more involvement (as at Corryhabbie) (Thorne, 1993; Thompson, 2007). Involvement, the reciprocal acknowledgement of the patients' knowledge and preferences and the development of a trusting relationship have been suggested to be mutually reinforcing (Thompson, 2007).

However, other patients (Martha and David) described feeling scolded rather than informed and involved by Vicki but wanted more information and involvement. These patients had questioned some aspect of Vicki's competence or care (see chapter six) which lends further evidence for suggestions that involvement and trust are mutually reinforcing. Martha provides a clear example of this, when, over the course of our

interview, she repeatedly returned to wondering why her treatment had recently changed and what that meant:

> I don't know what it was two years ago [but the doctor at the hospital] said that he would like me to go onto metformin... he just said I would like you to go on this tablet. I suppose I should have said why? But I didn't… sometimes I think I'm better not knowing a lot of things… And then when I saw Vicki she put me on gliclazide… I don't know why I got them and that's what I would like to know. And I should have really asked that but, I didn't.

Martha had first received no explanation from the hospital but also no explanation from Vicki. When the hospital introduced metformin she did not question this change, she thought she was "better not knowing". However, she explained that when Vicki introduced a second drug she then wanted to receive more information about both the metformin and the gliclazide. This may be because the increasing number of medications made her feel concerned that her disease was progressing as has been found elsewhere (Lawton et al., 2008a), but was also because of the lack of trust she had in Vicki's clinical knowledge. This lack of trust and desire for involvement was also reinforced by Martha's observation that her consultant was also questioning Vicki's clinical decisions. She told me that he had commented that he "wouldn't have put [her] on that" but since it was working he supported Vicki's decision. Hence, a lack of trust could also further a desire for more information and involvement, as has been observed by Thompson (2007).

The eight patients at Corryhabbie ranged in age from being over forty to over eighty. Most were over sixty but, whilst the two patients under sixty expressed a preference for involvement in clinical decisions, so did older patients such as Kathleen, who was in her sixties, George who was in his eighties, and Martha who was in her seventies. Patients at Corryhabbie had also been diagnosed for a wide range of time, with four diagnosed over twenty years ago, and four less than that; however, again the preferences expressed by these patients varied across their ages. Finally, whilst, as the examples of Daisy and Bert imply, patients' perceptions of the severity of their condition and experience of complications and side-effects of medications may also have contributed to patients'

preferences at Corryhabbie, this did not apply to all the patients and so I would argue that there was another influence.

At Corryhabbie there was an overall wider diversity of experience and preference for involvement in clinical decisions than at Silvenea. Thomas, Susan, George and Kathleen described being informed and involved in clinical decisions by Vicki, but not by the hospital. This is consistent with Vicki's description of her own role and her emphasis on education but also suggests that patients felt more involved than Vicki's account alone suggested. However, not all the patients felt this way. Bert and Daisy did not want to be more involved in clinical decisions, for reasons associated with their current perception or experience of their disease. Moreover, Martha and David wanted more explanation but felt that they had not received this in the past and that they had to take the initiative to gain this, rather than it being offered by the clinicians. This was related to the poor rapport and lack of trust they had in Vicki. Patients who had a good rapport with Vicki and trusted her tended to prefer involvement in clinical decisions with her. In Martha and David's case, a lack of trust appeared to be prompting a desire for more involvement. This is congruent with previous research (Thompson, 2007) that has suggested that whilst a lack of trust might prompt a desire for involvement, trust and involvement may be mutually reinforcing, and also suggests that involvement might be encouraged by the approach of the clinician.

Strathfinella

Five of the eight patients I interviewed at Strathfinella were diagnosed by Dr Sinclair, the retired GP, and all said that she had explained the condition to them when they were diagnosed. Some had then also pursued further information; for example, Joyce, who was in her thirties had researched the condition on the internet; Jack, who was in his late fifties, described how he would occasionally "wade through medical textbooks"; and Margaret, who was sixty, and Catriona, who was in her eighties, had both joined Diabetes UK and Catriona had also collected articles from scientific journals. Catriona

had also requested a monitor so that she could see the fluctuation in her blood glucose for herself on a daily basis and relate it to her diet.

However, not all of the patients at Strathfinella were equally motivated to find out about their condition. Jonathan, who was in his seventies, was less interested in finding out about the condition independently and commented that he could not imagine a group such as Diabetes UK providing "any more information than I can get from down the road". Also, although he used to self monitor his blood glucose regularly, he had reduced this to an occasional test which he explained was only out of curiosity as his health professionals had explained that self monitoring was "unnecessary" and he was willing to accept that as "they're the professionals". Katherine and Jeremy were the only two patients not diagnosed at Strathfinella and both had received some information and a blood glucose monitor from the professionals who diagnosed them. Both described finding this useful in explaining 'symptoms' and learning how food influenced their diabetes "especially in the beginning", but as they now felt they had learnt how to manage their condition and felt they could accurately interpret bodily symptoms, they now rarely used these monitors. In addition to receiving information about their condition at diagnosis, patients at Strathfinella received a letter after each review appointment outlining clinical results, such as their HbA_{1c}, blood pressure and cholesterol. Whilst all patients seemed pleased to be informed of their results, some also seemed a little confused as to why they were receiving a letter and what the measurements meant. This prompted further questions; for example, Katherine, like several of the patients I interviewed, showed me her most recent letter:

> Well, 6.6, that's what [my HbA1c] was the other day… But the blood pressure, 139 over 78. What does that mean? What's it supposed to be?
> [she turned to the back to the letter which noted 'ideal' values]
> Well, it says no change is required right enough. Oh, below 140. Well, mine's perfect… there was a load of questions that I wanted to know about being diabetic to start with. Like that thing there that says about your cholesterol and all the rest of it, all that stuff that she had done for me, like my blood pressure, what had all that got to do with diabetes and like when it

> said there about, say, 80 over 70 or whatever it was. How it would benefit me being diabetic if I could lower it?

The letter failed to explain what all the results meant, hence Katherine could not judge why these values were important or what she should do to control them. However, the very fact that this information was now being provided she, like all of the patients I spoke to (with the exception of Jeremy who had not experienced the earlier system), saw as an improvement:

> [Before they changed the organisation of care] you never ever got any of that slip saying what your blood pressure was and, that it was great and all that. That gives you a kind of a boost because see the last one, the one before that, she had wrote excellent on it and I was quite chuffed with myself. Excellent and I thought to myself, now what did I do this time that I never did before (..) before I started getting the' 'excellents', you know… I think it's better to know the likes of that cos then it gives you a bit of a boost and you know what to aim for.

Erica's annotations to the letter were highlighted by several patients as particularly encouraging and supportive. The letter also prompted Katherine to ask questions and may encourage her to pursue more information about her diabetes. The information and encouragement of the letter was valued but, without the knowledge to interpret the values themselves they could not be used effectively by patients to further their practices of self-care or to be more involved in treatment decisions.

Involvement in clinical decisions was only described by patients at Strathfinella in relation to decisions about medication which they had chosen to oppose, rather than being involved as a matter of course. Patients told me that their professionals always informed them when any changes were to be made in their treatment regimens, and for most this was sufficient involvement. For example, Jonathan responded to my question of whether he felt involved in planning his diabetes management saying:

> Oh aye, yeah. I mean, if there's something to be changed, they tell you it's to be changed and they tell you why.

He did not go on to express a desire for more involvement, but rather, as I noted above, adhered to the view that it was best left to the professionals. Similarly, Jack commented that he only wanted to know "if there's something wrong".

However, some patients did pursue more involvement when faced with changes to their medication. Yet, as at Silvenea, the onus fell on the patient to pursue this rather than involvement being offered as a matter of course. For example, Catriona was particularly adamant that she did not want to take metformin because it had previously made her feel "very unwell indeed". Hence, whilst, she had been convinced by Dr Scott to add metformin to the gliclazide she was already using, she was intending to use her blood glucose monitor to watch its effects "like a hawk". Similarly, Margaret described how she had eventually agreed to start using insulin as her GP recommended:

> So Pauline (a retired GP) and Erica were putting pressure on me to inject myself and I said, look, I don't want to do it. And Pauline said, it's your body, it's up to you, you don't have to if you don't want to. But then it was getting to the stage where I thought to myself, well maybe I should listen to what they're saying, maybe I should take their advice and just do it.

Margaret and Catriona both describe resisting professionals' attempts to change their drugs. In both cases their concerns were listened to and ultimately the choice to take a particular drug was their own, but they were not actively included until after the health professionals had made the decision to recommend a change to their regimes nor had they been offered other options. As mentioned in previous chapters, Catriona particularly wanted to be referred to a consultant in order to discuss her condition and the treatment options available to her this was perhaps partly because, she had not been able to have this discussion with her primary care health professionals. As she perceived her primary care professionals as over-reliant on clinical guidelines (see chapter six), this may well have been related to her perception that her primary care professionals did not have sufficient knowledge to have this discussion.

Patients at Strathfinella were interested in being informed about their condition and four of the seven interviewed had independently sought further information about diabetes. Although patients' descriptions of their care did not include being involved in discussing options and forming clinical decisions most seemed quite happy with this. The only two patients who expressed a desire for more involvement or information were Katherine and Catriona, both of whom had questioned the level of knowledge or competence of the GPs at Strathfinella suggesting that they did not fully trust them. Again this indicates that a distrust of professionals in specific ways could create or underpin a questioning attitude and hence prompt a desire for more involvement. However, Catriona's background as a pharmaceutical researcher may also have prompted her desire for more discussion and involvement.

Patients interviewed at Strathfinella again varied in age, the length and time they had had the condition and their experience and perceptions of the disease. However, again whilst changes in medication seemed to prompt a desire for involvement in some cases, the preferences most patients' expressed seemed to reflect their experience of being involved and the approach to involvement expressed by Erica and Dr Scott. As discussed in the first part of this chapter Erica and Dr Scott's approach emphasised providing information and explanation, but did not involve patients in treatment decisions. Interestingly, Margaret's and Catriona's accounts of being convinced to take medications also appears to reflect Erica's and Dr Scott's descriptions of "directing" patients towards the 'right' choice.

Comparison across the cases

Multiple factors such as age, experience of illness over time, the perceived severity of the illness and the experience of symptoms have been previously shown to influence patients' preferences for involvement in clinical decisions (cf. Say et al., 2006). I have considered the possible influences of these factors, which varied both within and across the case studies, in the data presented above. However, it is not possible to disentangle the extent to which these factors influenced patients' preferences based on the small

sample and qualitative case study methodology employed in this study. Nevertheless, the case study approach does enable me to consider patients' preferences for involvement in clinical decisions alongside their professionals' espoused approach to patient involvement and "patient empowerment". Analysing these alongside one another seems to suggest that patients' experiences of education and involvement are broadly consistent with the approach to "patient empowerment" espoused by the professionals at each practice. Moreover, my data suggests that patients' past experience of being involved in clinical decisions may be related to their preferred level of involvement, which is congruent with previous research (Porter et al., 1984; McKinstry, 2000). So, professionals' interpretations of "patient empowerment" and involvement may influence patients' own preferences for their role in being involved in clinical decisions.

Discussion and conclusions

This chapter has demonstrated how the concept of patient "empowerment" in health policy was interpreted by health professionals in each case study. I argued that professionals approached the concept of empowerment in three overlapping ways: as education, as choice, and as an impossibility. I suggested that these three approaches all tended to emphasise patients' knowledge of, and decision making based on, biomedical understandings of diabetes and its management as the key to "patient empowerment". The fully empowered patient was the one who was able to be involved in and make the 'best' treatment decisions because they were aware of the biomedical understanding of diabetes. As previously noted by Thorne et al. (2000), when professionals understand "empowerment" in this way it creates an ethical dilemma when they are faced with patients who chose not to follow the medical advice, or when they felt that patients did not have sufficient biomedical expertise to make informed decisions. Also, as Funnell and Anderson (2005) have observed elsewhere, the health professionals found it difficult to let go of the notion that it is their role to persuade patients to accept their recommendations. In all three case studies presented here professionals opted to 'guide' or 'direct' patient choice, or rejected the notion of empowerment entirely, and hence

ultimately continued to limit patients' involvement in clinical decisions. This was because they could not, or would not, give up responsibility for disease management and the patients' health. This perceived need to hold on to responsibility for the condition may also have been furthered by not only an interest in the patients' clinical health, but also a concern with meeting the financially incentivised QOF targets.

Mol makes a distinction between health care informed by a "logic of choice" and a "logic of care", which can be drawn on to try and understand the dilemmas expressed by professionals attempting to provide patient empowerment. In a "logic of choice" patients are treated as customers or citizens who make autonomous decisions based on the weighing of the value of one option against another; whereas, in a "logic of care", there is an ongoing interaction between patient and professional through which choices are made and unmade and treatment "doctored" to fit everyday life based on what is found to work in practice (Mol, 2008). Mol suggests that the logic of choice which currently pervades health policies like "patient empowerment", and which we have seen was central to professional understandings of this concept, is often at odds with the day to day provision of good "care" (Mol, 2008). Whilst the logic of care may also incorporate choice, generally it implies the need for an approach of partnership and negotiation.

In rejecting the notion of empowerment, or suggesting the need for patients to be guided or directed to the 'correct' decisions, the professionals in this study rejected the logic of choice which places all responsibility onto the shoulders of the patient. Yet, they equally did not discuss the kind of negotiation and exchange which would suggest a logic of care. This results from the inherent tension in the assumption that patients need to learn and be able to apply biomedical understandings of diabetes to be involved in clinical decisions. In order to achieve the partnership aspired to in health policy, more emphasis needs to be made of exchanging differing sorts of knowledge, the patients' knowledge of living with diabetes and the medical knowledge of the disease. Funnell and Anderson (2005) suggest that achieving this would require a significant shift in the medical paradigm.

However, as this research did not include observations of consultations, it is not possible to comment on the extent to which professionals enacted their claimed approaches to patient empowerment and involvement in practice. It is also unclear at what point health professionals may have reasserted a paternalistic approach in consultations. Although I was privy to patients' own assessments of the extent to which they were involved in clinical decisions, this is not always a good indication of the clinician's efforts to promote involvement, as patients may not be aware of the options and issues which the clinician chooses not to bring into the discussion.

From the patient's perspective, I have argued that, whilst the desire for involvement in clinical decisions may be influenced by multiple factors, there seem to be corollaries between professionals' espoused approach to "empowerment", patients' experiences of and preferences for information and being involved in clinical decisions. This is perhaps not surprising as previous research (Adams et al., 2001; Blanchard et al., 1988; Sainio et al., 2001; Entwistle et al., 2008) has also found that patients' experience of involvement can be related to their experience of being invited to be involved by their health care professionals. It is also congruent with findings that patients tend to prefer the style of their 'own' doctor, as found by McKinstry (2000), until, as Porter et al. found (1984), they have experience of an alternative. Moreover, Entwistle et al.'s (2008) interviews exploring what patients with diabetes understand involvement to mean have shown that being involved in clinical decisions may be related to the "ethos and feel" of consultations and the general perception that their "clinicians care about them" (2008, 273). This suggests that patients' experiences and interest in involvement in clinical decisions need to be understood within the context of their past and ongoing relationship with particular clinicians.

Montori et al. argue that patients' involvement in clinical decisions might be facilitated by an ongoing trusting "partnership" between a patient with a chronic illness and their health care team (Montori et al., 2006). However, there is little consensus in the literature over whether a trusting relationship acts as a barrier or facilitator to patients'

desire for involvement in clinical decisions in chronic illness (Calnan and Rowe, 2004). This is exemplified in Thompson's (2007) observations which have suggested that low levels of trust might lead to more desire for involvement, whilst high levels might be associated with a feeling that there is no need to be involved in clinical decisions. However, he also observes that "trust which emerges through greater involvement may create the conditions for a sustained desire for involvement" (Thompson, 2007, 1307). My data broadly supports these observations and suggests that trust seems to act in multiple ways. In order to understand this I would like to suggest a reorientation to the role of trust in facilitating or acting as a barrier to patient involvement. Previous research has tended to focus on levels of trust (high or low). I would like to suggest that instead we might find explanations for the differing relationships between trust and patients' preferred level of involvement by focusing on different sorts of patient trust.

Rowe and Calnan (2004; 2006) make a useful distinction between "affect" based trust, "grounded on relationships and affective bonds generated through interaction, empathy and identification with others", and "cognitive" based trust, "grounded on rational and instrumental judgements". These are broadly commensurate with trust based on a reflexive process of relationship building and trust based on a reasonable assessment of the trustworthiness of the trustee, outlined by Möllering (2006). Rowe and Calnan also (2006) propose that health policies, such as those emphasising shared decision making in chronic illness, are creating a shift in patients' trust of their professionals from affect-motivated trust to cognitive trust based on the sharing of information.

Across the three case studies I would argue that patients' varying preference for involvement in clinical decisions may be related to the differing basis for their trust, rather than just whether they had high or low levels of trust. At Silvenea I argued that patients had little desire for involvement because they trusted on the basis of their social assessment of Dr Harrison, rather than the sharing of information. Their trust was predominantly affect based. At Corryhabbie, those patients who felt involved trusted Vicki on the cognitive basis of shared information, and hence incorporated a larger

aspect of cognitive trust. At Strathfinella, patients' deference to their health professionals was generally supported by the provision of some information, but, I would suggest, was also supported by an affect based trust associated with the perception they were cared about. In all three case studies, the level, or presence of trust was also significant. Those patients who did not entirely trust their clinician sought further information or involvement. Moreover, this trust is embedded in the ongoing relationship between professional and patient and mediate links between professional's understanding of their role in disease management and the patient's expectations of their own role.

Chapter 9: Bridges between policy, professionals and patients

Introduction

In this thesis I set out to understand how health policies influenced the organisation of diabetes services in differing primary care contexts and how the resulting services might be interpreted by patients, potentially informing their perceptions and experiences of living with type 2 diabetes. In the literature review I presented this research as bridging two usually separate areas of academic concern: the interpretation and implementation of health policy by health professionals, and patients' perceptions and experiences of living with a chronic illness. In doing this, the thesis contributes to existing knowledge in three ways: first, it furthers our understanding of how health policy instruments interact with existing local precedents of primary care organisation and delivery, to shape the services provided to patients. Secondly, it contributes to the sociology of chronic illness by showing how local health service contexts can influence patients' perceptions of their care and, as a corollary to that, their condition and their role in managing that condition. Thirdly, by considering these two aspects alongside each other, the thesis provides a greater understanding of the factors influencing links between policy, practice, and patient experiences of the health services as part of their lives with a chronic illness.

In this thesis I have argued that local contexts of inter-personal relationships of trust, and professional identities and role expectations, influence both the organisation and provision of care and the meanings patients attribute to that care. In this final chapter I will summarise the findings of the thesis before moving on to a discussion of the themes which have cut across my analysis. I will then reflect on the strengths and limitations of the study design and suggest possible avenues for future research, before outlining the conclusions of the research.

Summary and synthesis

Incorporating diabetes care into the "generic and holistic" approach of primary care is the goal which health policies have aspired to in moving diabetes services into the community (Scottish Executive, 2002; 2003; 2005). Focusing first on the organisation of diabetes care within each general practice, I outlined both similarities and differences in the way in which the practice "holistically" incorporated diabetes care into "generic" general practice. All three practices maintained a register of diabetes patients, with a recall system, and organised diabetes reviews in special appointments in some form of clinic. Hence, at one level the provision of diabetes care was standardised in the manner that has been shown to be happening to the overall organisation of other general practices (Huby et al., 2008). However, there were also notable differences in how the diabetes clinics in this study were organised as part of each general practice. At Silvenea, the small, remote and rural practice, the full-time GP carried out all diabetes reviews and presented diabetes care as just another part of his *general* practice. At Corryhabbie, the large urban practice, all diabetes reviews were provided by Vicki, a nurse who specialised in diabetes and ran clinics at several practices in the area. Here diabetes care had historically been provided by secondary care and was still organised quite separately from everyday generic general practice. At Strathfinella, the village practice, diabetes reviews were carried out by Erica, the practice nurse, and could be organised for any time, rather than being arranged into a temporally defined clinic. However, clinical decisions were made in the absence of the patient in a later meeting between Erica and the GP. At each practice, diabetes care was organised as something separate from "generic" general practice to a greater or lesser degree. The extent to which it was separated reflected the ethos of general practice espoused by the professionals in each case, in particular, their conceptualisations of "holism" and "continuity of care".

Similarly, in each case study there was variation in the organisation of diabetes care which reached outwith the practice; for example, which allied health professionals were

involved differed across the cases, as did referral patterns to secondary care. These differences can be partly attributed to the location of each practice and the health professionals in the area. However, I showed that historical precedents of service organisation and professionals' trust in each other to fulfil expected roles were also important in shaping referrals and the perception of referrals as appropriate. Moreover, I found that professionals' stereotyped perceptions of each other across traditional boundaries (for example primary and secondary care) were informed by the implementation of previous health policies and associated assumptions about the motivations of the 'other' group. However, these generic perceptions sat alongside, and were often in contradiction to, trusting relationships between specific clinicians based on personal interaction and positive experiences of patients receiving appropriate care. These relationships of trust helped facilitate appropriate referrals across professional boundaries.

Inter-professional relationships also informed the use of locally written MCN clinical guidelines. In general I found that professionals expressed a preference for the MCN guidelines over national SIGN guidelines. I showed that this was partly because MCN guidelines provided advice in areas where SIGN's review of the evidence did not come to any conclusive recommendation and partly because they were more explicit in outlining exactly where patients could be referred in each locality. In addition, preferences for local guidelines can be understood in terms of professionals' trust in the people presenting the clinical evidence. Inter-professional relationships and traditional sources of advice, such as local consultant diabetologists, continued to be preferred as trustworthy sources of information for clinical practice. However, aspects of the guidelines which were perceived to represent the interests of one group of professionals over others were "ignored", as they were interpreted in light of the local context and local biases.

In chapter five I discussed some of the ways in which the QOF had influenced the organisation of diabetes clinics within each general practice, particularly focusing on

which professional provided patients' review appointments and why. Firstly, I showed that QOF work was perceived as a threat to the provision of 'personal care', so professionals at each practice explained that they had bracketed off meeting its requirements in order to protect or enable some personal care. The way in which each practice did this was related to the practice's ethos discussed in chapter four. In addition, I showed that QOF furthered the perception of diabetes care as routine and protocol driven in two out of the three practices and, drawing on Abbott's (1988) theory of professional jurisdictions, I proposed that this work posed a potential threat to the professional identity of the GPs. Hence, at Corryhabbie and Strathfinella diabetes care, or at least the routine aspects of diabetes care, was delegated to nurses. Only at Silvenea, where Dr Harrison viewed diabetes care as part of the generalist ethos of rural general practice and claimed that routine cases were indistinguishable from the non-routine, was it not delegated to a nurse.

However, whilst at both Corryhabbie and Strathfinella care was delegated to nurses, the way in which this was done differed. At Strathfinella, Erica provided the 'supportive' aspects of care and carried out the routine tasks of the review, but decisions involving professional judgement and discretion, such as decisions on prescribing, remained shared with the GP. In contrast, at Corryhabbie, Vicki essentially had sole responsibility for diabetes care. These differences reflected the differing extents to which the GPs at these practices had previously been involved in diabetes care and the ethos or approach to holistic care in each case. Organisations of care were not completely explained by the archetypical distinctions between nurses providing routine care and doctors exercising clinical judgement. It also involved negotiating roles locally, creating "fuzzy workplace jurisdictions" (Abbott, 1988, 72).

From patients' perspectives, I showed that diabetes care was not experienced as equally incorporated into "holistic and generic" general practice across the three case studies. Significantly, the separation of diabetes care from everyday general practice was not always presented negatively by patients. Rather, patients' preferences reflected both

their past experience of receiving care for diabetes and generic care from each practice, and they emphasised the value they placed on receiving services which were both competent and caring. I argued that past experiences of care from the practice and individual professionals, and receiving competent treatment formed the basis for patients to trust both particular professionals and teams at their practices. Where diabetes care was provided by patients' usual GP who was trusted, this trust was transferred to his provision of diabetes care. However, where the practice as a whole or particular GPs were perceived as uncaring or not competent, then trust was absent or partial. Hence, at Corryhabbie, where patients tended to view the practice as uncaring, diabetes care benefitted from being perceived as separate.

Patients' interpretations of the organisation of care between primary and secondary care and within general practice itself also revealed that their perceptions of professionals' expertise were informed by local contexts of care organisation. Patients' drew on stereotyped perceptions of the consultant as more expert than the GP, and the GP as more expert than the nurse, but these perceptions were also tempered by their previous experience of diabetes services, patterns of referral and knowledge of the training or experience of particular clinicians. Interestingly, a clinician's (sometimes assumed) personal experience of the disease also furthered patients' perceptions of their professional expertise.

This suggests that patients' perceptions of their professionals' expertise were being informed by local and inter-personal factors, as well as the general public discourse on the jurisdictions of the various archetypical professionals. As patients' perceptions of the expertise of their clinicians were informed by the local context, so their interpretations of referrals between these clinicians were also dependent on that local context. Hence, whilst not being referred to the hospital clinic might be interpreted as an indication that diabetes was not serious at one practice, at another where the GP was perceived to have knowledge equivalent to that of a consultant, a lack of referral would not be interpreted in this way.

Moreover, I argued that the trust which a patient placed in their clinician also informed their perception about whether they were receiving appropriate care. I went on to propose that, when patients perceived themselves to be receiving appropriate care (partly because they trusted their clinician), the organisation of this care could be drawn on (alongside multiple other factors) as an indication of the state of their condition.

In the final empirical chapter I considered professionals' interpretations of one goal of health policy, "patient empowerment", and placed these alongside patients' accounts of their experiences of, and preferences for, two aspects of empowerment: education and involvement in clinical decisions. I showed that professionals understood the concept of "patient empowerment" in three overlapping ways, as: education, choice, and impossible. These three approaches shared the assumption that an "empowered" patient was one who knew and acted on the biomedical understanding of diabetes and its management. Hence, when patients did not appear to be following medically prescribed regimens of self-care, professionals either assumed that they were not empowered and hence needed further education, or presented the patients' actions as resulting from a 'choice' which excused the professional from responsibility for their health and diabetes control. However, this latter position was not usually presented by the health professionals as acceptable. GPs, in particular, highlighted that patients generally did not have sufficient biomedical knowledge to make independent choices, for example, in terms of what medication to take, and hence resorted to paternalistically 'guiding' or 'directing' patients towards the 'correct' choice. The most pronounced directive approach was presented by Dr Harrison at Silvenea, who argued that it was his role to advise patients rather than expecting them to make decisions based on their lesser biomedical knowledge. Central to professionals' return to paternalism were notions of what their role was and what the patients' role was. Their role was to (educate) (offer choice) and guide the patient. The patient's role was to learn and act according to biomedical advice.

Patients' accounts of receiving education and involvement in clinical decisions broadly reflected the approaches outlined by their professionals. Interestingly, their preference for involvement also seemed to reflect these previous experiences. Patients' understandings of their role in diabetes care seemed to be informed by professionals' expectations of them. In addition, patients' desire to be involved in clinical decisions appeared to be associated with their trust in their clinician. I showed, as others have previously suggested (Thompson, 2007), that patients' trust could both act to encourage or discourage involvement, depending on whether it was based on experiences of sharing information and decisions or on expectations of the clinician as a person. Whether trust facilitated involvement or not could be related to the distinction which Calnan and Rowe (2004; 2006) have drawn between "affect" based and "cognitive" based trust.

This brief summary highlights various themes have repeatedly arisen from the analysis. These themes are: the importance of the local context of diabetes service provision; professionals' and patients' expectations of professional identities, roles and divisions of labour; and trust as a factor informing interpretations of the actions of others and facilitating social relationships across these divisions of labour. These themes might be usefully thought of as considerations which link the implementation of policy to patients' experience of health care and even their condition.

I will now go on to expand on these themes by relating my findings to previous research into professionals' organisation of health care and patients' experiences of health services and type 2 diabetes. By addressing each theme in turn I intend to make explicit the bridges across these two areas of academic concern.

Discussion and contributions: Local contexts, divisions of labour and trust

The role of the local context in which diabetes care is being organised and experienced is a central feature of this thesis and shapes both the divisions of labour in each case

study and the formation of trust between professionals and between professionals and patients. As the local ethos or approach to general practice influences these two other themes, I will discuss my findings in this area before going on to discuss divisions of labour and trust as themes which emerged across the three local settings, taking different forms in each.

Organisational sensemaking and making sense of organisation

In this thesis I suggested that professionals based in each general practice emphasised a differing ethos of general practice. Similar observations have been made in a previous ethnographic study of four general practices carried out by Huby et al. (2008). Like my study, they found that professionals at each of the four practices presented their organisation in a manner which emphasised differing defining characteristics of general practice, such as, holism, a concern with public health, or being at the forefront of new developments (Huby et al., 2008). Huby et al. (2008) drew on Weick's (1995) theory of "organisational sensemaking" in order to explain how these identities came to be constructed through the retrospective interpretation of actions and then go on to structure future action. Following Weick's (1995) theory, practice identity might be expected to develop over time as the organisation changes in light of external health policies. However, Huby et al. (2008) showed that changes and increasing standardisation in the organisation of general practice remained unrecognised in the professionals' narratives of their practice as an organisation. Huby et al. (2008) explained this discrepancy in two ways. Firstly, they attribute this to the gradual nature of the processes of standardisation. Secondly, they highlighted that the QOF reinforced some established features of general practice, such as its identity as a business and its promotion of public health; hence, it had "shifted rather than directly disrupted existing narratives" (Huby et al. 2008, 76). They also reflect that their data had perhaps emphasised the voices of some practice staff more than others due to difficulties during their fieldwork.

In contrast to Huby et al. (2008), I showed that the ideals or ethos espoused by staff at each practice did appear to relate to the particular manner in which they incorporated

diabetes care into general practice. Whether this was a result of an established ethos or retrospective sensemaking is difficult to ascertain and, as sensemaking is an ongoing and dynamic process, both being informed by and informing action, then it seems likely that the correspondence I noted is a product of this ongoing relationship. I have chosen to refer to this as ethos rather than sensemaking because the cross-sectional nature of my study does not enable me to comment on this ongoing process.

The relationship I observed between the organisation of diabetes care and the ethos espoused at each practice suggests, contrary to Huby et al.'s (2008) findings, that organisational sensemaking had not failed entirely. Whilst Huby et al.'s (2008) study focused on trends of change in response to the nGMS contract within the practice as a whole, I focused on the provision of only one aspect of general practice, diabetes care. This perhaps enabled me to observe continuing areas of difference lying under the surface of broader trends of standardisation. Rather than failing, I would argue that "organisational sensemaking" had moved to operate on a different level, where flexibility and choice in how QOF targets were met remained. Weick (1995, 12) observes that sensemaking takes place where choices have been made.

If aspects of the contract create a pressure for standardisation in one area they limit the choices available, perhaps shifting those areas of organising outside the range of choices informed by and informing "organisational sensemaking". Where choice and variation remained possible, sensemaking continued to (re)create a particular practice ethos, including local approaches to "holism" and "continuity of care", which influenced a particular approach to delivering diabetes care. Factors such as the practice's location in urban/rural and affluent/ deprived settings, and its size, both in terms of the number of patients and number of GPs and other clinicians, may have influenced its organisational ethos but further research is needed to further disentangle these relationships. For this thesis it is significant that variation was apparent in the understandings of holism and continuity of care at each practice, and that this had consequences for the organisation of diabetes care and patients' interpretations of that care. As discussed in chapters six and

seven, particular ways of organising of diabetes services could contribute to perceptions of care and competence and also to perceptions of the relative expertise of differing professionals.

Previous research (Lawton et al., 2009) into patients' experiences of receiving diabetes care found that, when patients moved from secondary to primary care, many were disappointed not to receive diabetes care from their usual or preferred health professional in general practice. Lawton et al. (2009) observed that diabetes care seemed to be in danger of being "ghettoized" into mini-clinics run by nurses rather than being holistically incorporated into the patients' general practice care. They (Lawton et al., 2009) argued that care was becoming more standardised and "less person-centred" and suggested that this might be attributed to the QOF. However, as the research was based solely on patients' accounts, Lawton et al. (2009) were not able to explain why diabetes care was being organised into separate, often nurse-led, clinics, nor were patients' accounts contextualised by knowledge of their general practices.

The case study approach of this thesis provides an explanation of some of the factors operating in individual general practices that might lead to the "ghettoized" diabetes clinics identified by Lawton et al. (2009). I have also shown that, under some circumstances, patients might prefer to have their care provided in a separate clinic rather than incorporated into their generic general practice. Again this is partially dependent on the local context of care provision. Patients' previous experiences of care, both for their diabetes and from a particular general practice, seemed to inform their preferences for diabetes service organisation. Previous experiences of care and competence also created a basis of trust in particular clinicians and practices, underpinning their preferences for care and the meanings they attributed to care organisation. Hence, the way in which a practice's ethos related to a particular way of organising diabetes care and went on to inform patient preferences for care and their trust in a practice or particular professional.

Divisions of labour and perceptions of expertise

In my presentation of the differing divisions of labour between professionals involved in diabetes care both within and outwith each of the general practices, two factors dominated the analysis: stereotyped views of other professionals and local negotiations of roles between specific individuals, both of which led to particular expectations of professionals and hence informed patterns of referral.

It has been suggested elsewhere (Charles-Jones et al., 2003; Grant et al., 2009) that, within general practice, the jurisdictional boundaries between doctors and nurses, particularly in providing chronic illness services, are becoming increasingly blurred. Charles-Jones et al.'s (2003) and Grant et al.'s (2009) organisational ethnographies of general practices highlight the influence of health policy on the divisions of labour between managers, GPs, practice nurses and administrators. These studies argue that recent policy influences and managerial changes within general practice are bringing about new divisions of labour based on the "appropriateness" of an individual's expertise to carrying out the clinical task, rather than their position as either a GP or nurse. This, with the added organisational incentive of achieving QOF targets, has, according to Grant et al. (2009), led to a readjustment of the clinical hierarchy behind a superficial façade of maintaining the existing order.

My findings are congruent with these earlier studies but also highlight the role of the local historical context of service provision in shaping the division of labour between nurses and GPs. In the practice where the GP had historically provided a diabetes clinic the delegation of that care to nurses may be less extensive than at the practice where there was a historical precedent of care not being provided by the GPs. Other factors, such as the professionals' approach to 'holism' and whether it was usual for different ailments to be treated by different clinicians in the practice, also seem to influence the division of labour. So, although the delegation of diabetes care to nurses was related both to factors identified elsewhere (Charles-Jones et al., 2003; Grant et al., 2009) (such

as the routine nature of the work), it was also influenced by the local and historical context of care provision.

Similarly, divisions of labour between primary and secondary care appeared to reflect local perceptions of the other sector as a whole and individual relationships across these professional boundaries. On the one hand, my findings resemble those of Dartington's (1979) study of referrals across the secondary-primary care interface. Like Dartington (1979) I found that the way in which different professional groups defined their area of expertise influenced the organisation of care. However, I also showed that both within and outwith the general practices expectations of individual clinicians were mediated by multiple factors. For example, stereotyped perceptions of the 'other' sector were informed by interpretations of their motivations, particularly in relation to previous and current health policies. Yet alongside these stereotypes, I showed trust between individual clinicians also played an important role in shaping referral patterns and in determining where professionals turned for clinical evidence and advice.

My findings in relation to professionals' claimed use of clinical guidelines and preferred sources of clinical advice reflect those of some previous studies (Fairhurst and Huby, 1998; Gabbay and le May, 2004; Jackson et al., 2004). Like Fairhurst and Huby's (1998) study of GPs' use of clinical guidelines for hypercholesterolemia, I found professionals in my research claimed to prefer "local guidelines produced by people known" to them over "national guidelines even when these were produced by people of acknowledged national and international repute" (Fairhurst and Huby, 1998, 1133). Fairhurst and Huby (1998) suggest that social processes of building a local consensus are important in incorporating evidence from research into every day clinical practice. Similarly I suggested that MCN guidelines were preferred because they represent just such a local consensus. My findings are also aligned with Jackson et al.'s (2004) focus group study of Canadian family doctors discussing the use of clinical evidence. Jackson et al. (2004) showed that "subjectively-based perceptions of trust" (Jackson et al., 2004, 239) informed doctors selection and use of clinical evidence and it is trust in the source of the

clinical guidelines which seemed to underpin the preference for local guidelines in my research. Similarly, like previous research (Fairhurst and Huby, 1998; Gabbay and le May, 2004; Jackson et al., 2004), I also found that professionals claimed to turn to locally recognised specialists for advice in addition to the guidelines. These specialists had come to be trusted over repeated experiences of patients' receiving appropriate care, inter-personal communication and shared experiences of training and I suggested that this inter-personal trust meant that they were more likely to be turned to for advice. Finally, like previous studies (Fairhurst and Huby, 1998; Jackson et al., 2004), the biases which guidelines were perceived to represent also influenced their use. For example, whilst these previous studies point out that guidelines produced by pharmaceutical companies were treated with suspicion, I suggested that those areas of clinical guidelines which seemed to preferentially serve the interests of one group of professionals were not trusted.

This section aimed to discuss the multiple factors influencing professionals' division of labour in providing diabetes care. So, in order to meet the aims of this thesis, I will now address the question of how professionals' divisions of labour were perceived by patients and the significance of this for their experience of their health care and diabetes. I will then go on to continue my consideration of divisions of labour to the division of labour between patient and professional.

Interpreting the division of labour between health professionals

As summarised above, the resulting patterns of referral and divisions of labour between the clinicians involved in diabetes care were interpreted and given meaning by the patients receiving that care. I argued that patients interpreted local patterns of referral and drew on their personal knowledge of their health professionals to inform perceptions of their professionals' relative expertise. Some patients then interpreted the organisation of their care in relation to these differing levels of perceived expertise as an external indicator of the state of their condition.

Lawton et al. (2005) have previously observed that some asymptomatic patients, newly diagnosed with diabetes, interpreted the organisation of their care as an external indicator of the severity or progression of their condition. For example, they suggested that, as care provided in general practice was perceived as less expert than that provided in hospital, some patients receiving care in this setting interpreted this as an indication that their diabetes was not so serious after all. My findings support this earlier study but highlight the locally contingent nature of patients' perceptions of expertise. This applied not only to the perceived difference in expertise between GPs, hospital consultants and DSNs, but also to perceptions of the expertise of nurses and doctors based within general practice.

On one level I suggested that patients' perceptions of their professionals' expertise reflected common stereotypes, but patients also drew on their experiences of referral and personal knowledge of individual health professionals to inform their perceptions of their expertise. For example, at Corryhabbie, some patients did suggest that Vicki was more specialised in diabetes care than the GPs. However, she was perceived as less expert than the doctors at the hospital clinic. At Strathfinella the pattern was different. Here Erica continued to be perceived as having less expertise than the GP. This can be attributed to the fact that patients were referred to a GP when they needed to make changes to their diabetes regimen. I also noted that patients tended to perceive their health professionals as having greater expertise or trusted their advice more if they were known to have personal experience of the condition, for example Dr Sinclair at Strathfinella. Patients drew on a similarly complex understanding of professional roles as the professionals themselves. Patients' perceptions of their professionals' expertise resemble the professionals' own way of explaining the organisation of diabetes care. Like the patients, I showed that GPs at two practices explained the organisation of their diabetes care by drawing on contradictory perceptions of the nurses providing the practice's diabetes care. On the one hand they explained that nurses carried out this work because it was routine and did not require professional discretion, while on the other

hand they also acknowledged that the nurses at their practices had greater knowledge of diabetes than themselves and hence were better able to make clinical judgements.

These findings sit in contrast to Abbott's (1988) assertion that the public only note the stable archetypical differences between professionals. He suggests that, should the blurring of professional jurisdictional boundaries be noted by the public, this would lead to a shift in public perceptions of the archetypical divisions of labour between the professions. Hence patients' recognition of the variation in expertise of specific clinicians might be interpreted as evidence to support Grant et al.'s (2009) suggestion that the boundary between practice nurses and GPs is shifting. However, the extent to which traditional boundaries were blurred was related to local patterns of referral and did not extend to generalised perceptions of the roles and jurisdictions of doctors and nurses. Whether locally situated perceptions of nurses' expertise will become widespread and generalised to the profession as a whole is a question which can only be answered by longitudinal research.

What emerges as significant from the perspective of the research questions addressed in this thesis is that, as patients' perceptions of their professionals' expertise in diabetes care were informed by local factors, so the interpretation of health care organisation as an indication of disease severity or progression was also locally situated. Where receiving care in secondary care at one practice might be interpreted as a sign of disease progression (for example at Silvenea), this was not the case where there was an established practice of patients receiving secondary care appointments as a matter of course (as at Corryhabbie). Moreover, I have argued that patients' trust in the clinician referring or making changes to their diabetes care also influenced the interpretation placed on those changes as an indication of disease progression. Hence, local interpretations of health care organisation and professionals' perceived levels of expertise should be taken into account as another factor amongst the many which have been previously identified as influencing patients' perceptions of their condition (Hunt et

al., 1997; Lawton et al., 2008; Murphy and Kinmonth, 1995; Parry et al., 2004; Parry et al., 2005; Savoca et al., 2004).

Divisions of labour between professional and patient

I addressed the division of labour between professional and patient in relation to the policy of "patient empowerment" in chapter eight. Like the divisions of labour between health professionals, which were shaped by perceptions of professional jurisdiction and identity, and the roles each expected of the other, so the division of labour between professionals and patients can be understood in terms of role expectations.

I have shown that, despite adopting slightly different approaches to patient involvement, professionals at all three practices resorted to some degree of paternalism. Along similar lines to previous writers who have discussed the difficulties of enabling "patient empowerment" (Anderson and Funnell, 2005; Thorne et al., 2000), I showed that this reflected professionals' assumptions that ultimately it was their role to advise and convince patients of what they thought was the 'correct' approach to disease management. I argued that the particular way in which professionals understood their role seemed to be related to patients' experiences of involvement in clinical decisions, which in turn influenced their subsequent preferences for being involved.

Previous studies (Say et al., 2006; Thompson, 2007) show that not all patients want to be involved in clinical decisions to the same extent. As I discussed in chapter eight, multiple factors, such as a patient's age or socio-economic status and the nature of their illness (chronic or acute, or changes suggesting disease progression), may influence their desire to be involved in clinical decisions (Say et al., 2006; Thompson, 2007). Moreover, involvement might also mean a variety of things to a patient depending on the situation, from just being informed about results and changes, to sharing clinical decisions, and to even making clinical decisions autonomously (Entwistle and Watt, 2006; Thompson, 2007).

Entwistle and Watt (2006) argue that the conceptualisation of patient involvement should be broadened to include differing understandings of what it means to be involved. Entwistle and Watt (2006) observe that previous research into patient involvement has tended to focus on patient-professional communication in consultations and patients' contributions to decision making, with some studies considering clinician's efforts and contributions to decision making. However, they theorised that both patients' and clinicians' views and feelings about their roles in decision-making, and their relationship with each other, may also influence patients' subjective perception and desire to be involved in clinical decisions, relating to the establishment of a "partnership" between patient and clinician and the communication between the two (Entwistle and Watt, 2006).

In chapter eight I argued that patients' experience and desire for involvement appeared to reflect the approach of their professionals to patient involvement and empowerment. This finding supports Entwistle and Watts (2006) conceptual framework and, as discussed in chapter eight, also resembles the findings of Entwistle et al.'s (2008) interviews with patients with diabetes. I went on to argue that the accord I found between patients' desired level of involvement and professional approaches to involvement seems to be related to the ongoing relationship between the patient and professional. This sits in line with Montori et al.'s (2006) suggestion that approaches to shared treatment decision making in chronic illness should be understood within the context of a trusting "partnership" between patient and professional. Yet, my analysis also furthers our understanding of the role and nature of trust in acting as a barrier or facilitator to patient involvement.

Patients' who desired less involvement tended to express what Calnan and Rowe (2004) refer to as "affect" based trust in their professionals. This trust was built on previous experience of having their expectations of care and competence from a health professional or 'team' of professionals at their general practice met, as at Silvenea. However, this trust is not necessarily based on the sharing of information or informed by

some external assessment of the professionals' ability. In contrast, those who had experienced involvement, for example some patients at Corryhabbie, tended to continue to want involvement and expressed a more "cognitive" based trust. This trust was based on the sharing of information between patient and professional. Trust of a particular type, and a desire, or lack of desire for involvement, seem to be inter-related. Whilst previous studies have noted a relationship between trust and patients' desire for involvement or interest in managing their own condition (Montori et al., 2006; Thorne, 1993), these studies have tended to focus on whether involvement was related to high or low levels of trust, few studies have suggested that differing bases of trust might inform differing desires for involvement. This thesis furthers this area of knowledge by offering further evidence that the basis of patients' trust in their health professional is important to whether that patient wants more or less involvement in clinical decisions.

Trust has been a recurring theme across this thesis. I have suggested that trust has facilitated social relationships between professionals organising care and between patients and their health professionals. However, as the above discussion of differing bases for patients' trust illustrates, I have discussed multiple forms of trust facilitating differing social relationships. Hence, whilst I would suggest that trust can be taken as a theme to trace the influence of health policy through professional organisations to patients' experiences of care, there are significant differences in the bases and expectations of trust which relate to the differing social relationships involved in the provision and experience of diabetes care. I will reflect on these in the next and final section of this discussion in order to outline what the differences are and to demonstrate how the concept of trust might serve as a useful bridge for understanding professional organisations of care and how these related to patients' experiences of chronic illness.

The role of trust

This thesis did not set out to study trust but it emerged as important in understanding both patient and professional accounts of providing and receiving diabetes care. As noted in the preface to chapters five, six, seven and eight, Möllering (2001) suggests that

trust "is a mental process of three elements…: expectation, interpretation and suspension". Interpretation is the basis of trusting, the 'good reasons' to trust which may inform the expectations ultimately made. Suspension is the step taken by the truster to bracket uncertainty and move from their interpretations to a state of expectation; it is the acceptance of risk and acting despite that risk. Finally, expectation is the outcome, the state of trusting, and Stzompka's (1999) theory of trust, delineates different sorts of expectation. He proposes that there are three varieties of expectation: "instrumental", "axiological" and "fiduciary".

I have argued that professionals' preference for local clinical guidelines over national SIGN guidelines and their referral practices were influenced by trust. Professionals' trust in other clinicians to whom they might refer patients or receive referrals from, involved the expectation that they would provide the care anticipated of their role. For example, DSNs expected GPs not to try and provide diabetes care beyond the boundaries of their professional knowledge and hence their jurisdiction. Similarly, professionals expected guidelines to provide a summary of the best known clinical practice and hence guide appropriate care.

These expectations were based on both institutional and inter-personal assessments of the potential trustee and have been outlined in the thesis summary above. To summarise, trust might be based on perceptions of the expertise of the professional being referred to, but this tended to be enhanced by interpersonal factors, such as past experiences of patients receiving appropriate care and communication across professional boundaries. Similarly, professionals' trust in local clinical guidelines was based partly on the perception that they represented scientific knowledge and partly in the interpersonal professional relationships that they represented. In both referrals and use of the guidelines, the perceived motivations of other clinicians also acted as a basis to support or undermine trust.

These expectations, as I noted in chapter five, are "instrumental" and "axiological" (Sztompka, 1999) in nature. Professionals expect their colleagues to be both competent and efficient in working towards a shared goal, and, in doing this, to draw on shared moral values of placing the patient's health and wellbeing before personal interests. As with any trust, health professionals risk these expectations not being met; they suspend uncertainty and trust.

In this thesis I then went on to discuss patients' trust in health professionals and their general practice 'teams', a form of trust that involves quite different expectations and suspension to the professionals' trust in each other. Patients' trust in their health professionals is generally agreed to involve the expectations that they will receive health care which is both competent and caring (Brownlie et al., 2008; Davies and Rundall, 2000; Guthrie, 2008; Sztompka, 1999, 53). In contrast to the professionals' trust in each other, patients' expectations incorporate all three of the varieties of trust outlined by Sztompka (1999). Patients have instrumental and axiological expectations that their professional will be competent and act in a manner morally appropriate to their role. However, in addition to this, patients' trust involves a fiduciary expectation of care. This is an expectation that, to paraphrase Tronto's (1993) definition of *care*, the professional will take the concerns and needs of the patient as the basis for action. It is this fiduciary expectation which is particularly notable in contrast to inter-professional trust and which also means that patients' suspension, their "leap of faith" (Möllering, 2001), seems to be greater and more risky than that undertaken by the professionals. Patients' trusting expectations are formed from a position of vulnerability (Hall et al., 2001), which appears to be greater than that of professionals choosing to trust each other. Patients do not usually have the same knowledge as their health professionals and rely on them to provide information and offer advice and medications, essentially to act in their interests. This reflects the continuing and perhaps unavoidable asymmetry of power in the patient-professional relationship (Måseide, 1991).

Patients' trust in health professionals and professionals' trust in each other entails similar axiological and instrumental expectations, but patients' trust in health professionals also involves fiduciary expectations. Interestingly, the data presented in chapters five, six and seven suggests that both patient and professional trust is based on similar combinations of knowledge and prior personal experience. Both are informed by knowledge of the (other) professionals' training and prior experience of appropriate healthcare being provided. However, for patients I also found that trust in the expertise of health professionals was informed by knowledge of that professional's personal experience of diabetes. As Brownlie and Howson (2005) have observed, institutional factors and perceptions of a professional's clinical knowledge act as , a "warrant of trust" which "anticipates a process of trust building" through an inter-personal relationship over time (Brownlie and Howson, 2005, 229).

Whilst there are similarities and differences between inter-professional and patient-professional trust, there was also variation in the bases of patients' trust in their health professionals across the case studies. As argued above, I found that some patients' trust was based on a personal assessment of their clinician, whilst others' was related to receiving information, sharing information and making decisions with their health professional(s). Significantly these different sorts of trust seemed to be related to their desire to be involved in clinical decisions. In addition, as discussed in chapter seven, existing trust in a health professional appeared to influence patients' perceptions of the appropriateness of their care organisation and, hence, the meanings which they attributed to that organisation as an indicator of the state of their condition.

Whilst trust takes various forms, it bridges understandings of both the implementation of policy and patients' interpretations of their care, and their willingness to be involved in their healthcare. Future research might continue to explore the links between these areas of concern through a consideration of the role of trust. However, before moving on to discuss more suggestions for future research, it is important to reflect on the strengths

and limitations of the study design in order to contextualise the findings discussed above.

Reflections on the research

In order to reflect on the strengths and limitations of my research strategy and the analysis emerging from this, it is useful to return to the initial research questions:

1. In what ways do health policies influence the organisation and provision of diabetes services in differing primary care contexts?

2. Do patients' perceptions and experiences of their primary care diabetes services influence the way they perceive and experience their condition, and if so, how?

By addressing these questions alongside one another, this research aimed to create a linked understanding of professionals' organisations of diabetes care and patients' experiences and interpretations of that care. It also aimed to understand how the organisation and experience of diabetes care might be related to the local context in which it was provided. The multiple case study design I adopted was well suited to addressing these aims. By studying the organisation and experience of diabetes care in-depth in each case study, I was able to understand how these came to be influenced by the local context of each case. Moreover, the cases recruited to the research differed sufficiently in the organisation of diabetes care to highlight multiple factors which could influence the organisation of care and the ways in which differing organisations are interpreted by patients. Continuing with my original plan to carry out four case studies would, I believe, have provided another example of variation in the organisation and experience of diabetes care.

Although the three cases discussed in this thesis are quite different they were all located in quite affluent areas and none were based in a city centre. Had a fourth case been conducted, differences in the organisation and experience of care which might be

expected in a more deprived inner city area might have been explored. As noted in the methodology chapter, research has suggested that the inverse care law continues to be perpetuated (Mercer and Watt, 2007; Goyder et al., 2000; McLean et al., 2006). For example, general practices in more deprived areas have been performing less well in the more complex QOF targets, such as glycaemic control in diabetes (McLean et al., 2006). Moreover, research into patients' experiences of living with type 2 diabetes has shown that economic factors can act as important facilitators or barriers to self-care practices (Drummond and Mason, 1990; Anderson et al., 1995). An inner city location might also influence the organisation of care for diabetes as there may be greater ease of access to secondary care diabetes services and allied health care professionals. However, whilst it would have been interesting to explore more variation, the first three practices recruited provided sufficient variation for the purposes of addressing my research questions. In addition, it would not have been possible to analyse the quantity of data collected from four cases within this PhD study, hence, I stopped data collection after three cases studies. The differences in the organisation and experience of care between practices in affluent and deprived areas would provide an interesting focus for further research.

The cross-case analysis employed in this study enabled me to identify common themes which influenced the organisation and experience of care, linking professional and patient interpretations and experiences across all three cases in a way which would not have been possible using other designs. Had I adopted the approach of many previous studies and simply interviewed patients or health professionals I would not have been able to identify many factors influencing care provision and the experience of healthcare. I would not, for example, have identified the nuances in patients' perceptions and preferences for having their diabetes care incorporated into their "generic" general practice or not. Understanding how the provision of diabetes care and experience of that care are inter-related and shaped by particular local contexts would also not have been possible had I recruited diabetes patients and professionals irrespective of their particular general practice. Finally, without the cross case comparison, which was enabled by studying three cases rather than just a single case, I would not have identified the

common themes of the local historical context, division of labour, and trust, which I have argued influence both professionals' interpretation and implementation of health policy and patients' experience of their healthcare and perceptions of their condition.

Within each case study I employed a combination of methods: interviews, non-participant observation and an analysis of relevant documents. As discussed in chapter three, these methods were appropriate for addressing my research questions. However, it is pertinent to consider the credibility of the analysis (Bryman, 2004; Seale, 2005), which has been presented in this thesis by considering the strengths and weaknesses of these methods, the sample involved, and whether the account I have given can be supported by the data collected.

In each case study the multiple methods employed worked well in a mutually informing manner. My non-participant observation within each practice in particular enabled me to identify and explore topics in interviews with health professionals which may have gone un-noticed, such as, the informal communication between professionals to coordinate care, and the use of local knowledge to tailor the time of appointments to particular patients. My observations also gave me a sense of the practice as a whole which furthered my understanding and facilitated my communication about the practice with patients. My reading of policy documents and local guidelines helped to inform and facilitate my interpretation of my interviews with health professionals. Finally, my interviews were the appropriate method for accessing the individual perceptions and experiences of patients and professionals. The use of multiple methods and a focus on each case study in turn enabled me to develop a contextualised and nuanced understanding of the cases, and, in turn, facilitated a detailed cross-case analysis. There were also other benefits that emerged from combining methods in each case study which I outlined in chapter three; for example, observations facilitated the development of a rapport with practice staff and this, I believe, improved the depth and quality of my interviews with these staff. However, the case study approach also presented a considerable challenge in terms of the time needed, not just to conduct the cases, but

also to undertake the analysis which was detailed and required data to be compared and contrasted both within each case and across the cases. In addition, the particular methods within each case study were not always straightforward to employ, as I discussed in my reflections on data collection in chapter three. However, rather than repeating that discussion here, I will now consider some of the limitations of the research design.

Firstly, within each case study the sample of patients interviewed was relatively small. Eight is generally too small sample to stand alone in enabling a detailed understanding of patients' experiences of diabetes or diabetes services. Hence, one might argue that more patients should have been included in each case study. Yet, as highlighted in chapter three, patients' accounts of their diabetes care were interpreted within the context of the case study as a whole and alongside professionals' accounts of diabetes care and my own observations. For example, my presentation of a health service's influence on patients' desire to be involved in clinical decisions is based on a combined understanding of professionals' approaches to empowerment and patients' experiences and wants relating to that. However, some observations were possible which did not relate to each individual case. For example, in chapter seven I discussed the apparent influence of biography, medications, and physical changes on patients' perceptions of the progression and severity of their condition; these observations were drawn across all three cases, i.e. from the overall sample of 23 patients.

If I were to repeat this research, I would seek to ensure that the sample of patients interviewed were more directly comparable across the cases in terms of factors such as age, socio-economic status and length of time since they were diagnosed. Whilst in my analysis I have taken care to point out alternative explanations for observations, such as patients' preferences for non-involvement in clinical decisions, it is possible that my findings were skewed by the differences between the samples at each practice. For example, at Silvenea only one patient was under the age of sixty, whilst in contrast at Strathfinella four patients were under sixty years old.

Secondly, if I were to repeat the research I would increase the length and breadth of my observations in each general practice. A longer period of observation would have added to the quality and depth of my understanding of each of the case study practices. This is particularly true of Corryhabbie, which was a particularly large and complex organisation that was difficult to come to grasps with in a two week period. Extending my observations to include the consultations between patients and clinicians would also potentially have improved the research in two ways. It would have furthered my understanding of the relationship between patients' experiences of being involved in clinical decisions and professionals' approaches to empowerment by enabling me to compare professional and patient accounts with my own observations of what they did. It would also have enabled me to extend my understanding of diabetes care to include more information about clinicians not based in general practice, providing more information about the role played by professionals such as the dietician. However, this approach might only be appropriate if fewer case studies were included as the quantity of data across three cases would be in danger of becoming unmanageable for one researcher.

One final change which I would make to the research design would be to carry out more "respondent validation" (Bryman, 2004). Following my analysis of each case study, one of the general practices requested some feedback from the research. So, I wrote a report outlining how I understood their diabetes care to be provided and included aspects of their care which patients highlighted as areas of concern or as particularly good. I have discussed this report with the diabetes lead nurse at this practice and she was very positive about it. She recognised my description of their service as accurate and reported that my analysis of the patients' views of the service seemed plausible, making her think about the way they organised their care from a new angle. Whilst this small amount of respondent validation suggests that my interpretation of the practice was a dependable account, I regret that I did not carry out a similar form of feedback with the professionals at the other practices and patients because of limited time and resources. I hope that

following the completion of this thesis I will be able to return to these practices to discuss my findings and to perhaps carry out some further research relating to these.

Whilst the research design employed has various limitations which I have learnt from as part of the process of the PhD, it also had numerous strengths and was well suited to addressing my research questions. Further research might go on to further refine the multiple case study approach as a methodology which has the potential to offer many insights into the links between healthcare organisation and patients' experiences of illness. I will now suggest other possibilities for further research before concluding this thesis.

Avenues for future research

The research presented here might be taken forward in a number of ways. Firstly, a piece of longitudinal research might consider how the organisations of diabetes care develop and change over time as practices continue to adjust to existing and new health policies. In chapter five I noted that other studies (Grant et al., 2009; McDonald et al., 2009) have suggested that the nGMS contract is shifting the identities and boundaries between GPs and nurses in general practice. This might mean that the organisation of diabetes care within the three case study practices in this research will continue to change, with nurses perhaps taking on more responsibility for diabetes across all three case studies. Further research might return to the case studies to study any changes in the organisation of care since the original study and also to investigate whether patients' perceptions of their care had also shifted in light of these changes.

Another potential area to be explored through longitudinal research would be to investigate whether patients' perceptions of the archetypical jurisdictions and expertise of doctors and nurses are shifting. Will patients' experiences of receiving care from nurses which previously lay within the jurisdiction of GPs, eventually lead to differing perceptions of the archetypical roles of doctors and nurses as Abbott's theory (1988)

implies, or are their perceptions of professional jurisdiction just linked to particular professionals in the local context?

Another way in which the research presented here might be furthered would be to expand its consideration of professionals involved in influencing the way policy is incorporated into diabetes care. This thesis suggested that the local, historical relationships between primary and secondary care were important influences on the organisation of diabetes care in each study. Hence, further research might investigate the relationship between primary and secondary care further, for example by interviewing hospital consultants. It might also further consider the role of MCN managers and the MCNs themselves, as these also emerged as factors shaping the organisation of diabetes care.

Whilst the research presented here has focused on the implementation of health policy, it should also be noted that evaluations of this implementation, for example through Quality Improvement Scotland's audit of Health Boards (NHS Quality Improvement Scotland, 2004), will in turn inform future policy. Hence, further research might aim to link the consideration of policy implementation and meaning discussed here to the factors influencing the development of health policy.

Further research might also attempt to test whether the interpretations of diabetes care presented by the patients in this study were shared by the rest of those diagnosed with diabetes at each case study practice. This could take the form of a questionnaire survey which might then be further developed into a survey tool to investigate these relationships on a larger scale. For example, it might further investigate and develop generalisations about how patients' experiences of type 2 diabetes services, and the significance of these, are informed by aspects of the local contexts of professional approaches to providing and organising care. This survey would test and take forward some of the hypotheses which have emerged from this research.

Conclusion

This thesis outlined some of the multiple factors influencing the organisation of diabetes services in three primary care settings. It then went on to consider how the particular organisation of care in each setting was interpreted and given meaning by patients receiving that care. Previous research has tended to focus either on how professionals go about organising health care, or on patients' experiences of living with a chronic illness in the context of their wider lives. However, a few studies (Lawton et al. 2005; Hart, 2001) have also related patients' interactions with the health services to their perceptions and experiences of their condition. In this thesis I have contributed to this area of research by adding a more nuanced way of understanding the ways in which health care organisation can be interpreted and given meaning by patients within local contexts. This furthers understandings of the role health services can play in influencing patients' perceptions of their condition, and their role in managing that condition. It also reemphasises previous calls (Lawton et al. 2005; Hart, 2001) for research to reach beyond the 'insider perspective' and consider the role of the health services in patients' experiences of chronic illness.

A further important contribution of this thesis has been to place a consideration of professionals' interpretations of policy alongside patients' experiences of care each within local and historical contexts. This has highlighted that in order to understand the influence of health policy on the services patients experience it is necessary to consider how policies are mediated by local contexts of healthcare organisation.

Moreover, my multiple case study research design and cross-case analysis has enabled me to identify three overlapping themes as important to both the organisation of diabetes care and to patients' interpretation of that care. The first is the importance of the local and historical context of service organisation and the meanings created within this context. This includes how local interpretations of the professional ideals of general practice inform organisations of diabetes and the meanings which patients attribute to

the resulting organisation. The second theme is closely related to the first and involves understanding how both archetypical and locally constructed understandings of professionals' roles and jurisdictions influence the daily negotiation of divisions of labour in diabetes care. This can be placed alongside patients' perceptions of differing professionals' expertise, which are informed by both professional stereotypes and experiences of referrals and knowledge of professionals in their local setting. Moreover, patients' understandings of differing professionals' expertise under some circumstances inform their interpretations of care as an indication of their disease progression. Finally, considering the role of trust in its various forms has provided an avenue through which to consider links between the implementation of policy and organisation of care by professionals, and patients' experiences of the health services and what these mean in terms of their diabetes and their role in its management. These themes have the potential to provide new avenues of research aimed at a more 'holistic' understanding of the experience and provision of healthcare and how these are influenced by health policy.

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Appendices

Appendix I: Recruitment letter for general practices.

1st March 2007

COLLEGE of
HUMANITIES and SOCIAL SCIENCE

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Dear (Practice Manager and senior partner) ,

I am a PhD student at the University of Edinburgh carrying out research about diabetes care in Scotland. The study is entitled *Experiences of Diabetes Services in Scottish Primary Care* and is a qualitative research project funded by the Scottish Executive. This research will provide an understanding of not only the patients' perspectives of the care they receive for type 2 diabetes, but also health professionals' experiences of providing diabetes services in the context of current health policies.

The reorganisation of the diabetes services and the payment incentives associated with the new GMS contract have not yet been fully researched from the perspective of patients and their health care professionals. This research will aim to further our understanding of how health policies are affecting the way type 2 diabetes care is being organised and provided on a day- to day basis in a range of primary care settings in Scotland

The proposed study will involve 4 general practices, in two Health Boards. In each Health Board area, one practice will be selected from a rural area, and one from an urban area. The practices themselves will act as the principal cases through which diabetes care will be explored. Each practice will be involved in a short period of non-participant observation, interviews with the health professionals involved in type 2 diabetes care and recruiting patients with type 2 diabetes for interviews. If you would be interested in taking part please read the attached information sheet and get in touch.

I look forward to hearing from you!

Heather Milne.

e.mail: s0198190@sms.ed.ac.uk. Telephone: 0131 651 3205

Appendix II: Patient recruitment letter

1st March 2007

COLLEGE of
HUMANITIES and SOCIAL SCIENCE

Heather Milne
c/o Dr. Andrew Thompson
The Adam Ferguson Building
University of Edinburgh
Edinburgh EH8 9LL
Scotland UK

Tel. (0131) 651 3205
Tel 2 (0131) 57 3120
Email s0198190@sms.ed.ac.uk

Dear

I am a PhD student at the University of Edinburgh carrying out research about diabetes care in Scotland, funded by the Scottish Executive. The study is entitled *Experiences of diabetes services in Scottish Primary Care* and will focus on the care you receive from your GP and within the community rather than hospital services. I would like to find out how recent policy changes have affected both patients and health care professionals. Have you noticed any changes in the care you receive over the past four years, or has your diabetes care always been the same?

I am interested in finding out what is important to you in your diabetes care and whether you find it easy to access all the services you need to help you manage your diabetes. I am looking for people to take part in my study who have had type 2 diabetes for at least 5 years and hence will have had the opportunity to notice any changes in their care. If you would like to take part, this will involve an interview lasting approximately one hour at a place and time of your choosing.

The results of this study will form the basis of my PhD thesis and may be used to develop a survey instrument for health professionals to use to assess care across the country. The conclusions of the study will also be reported to the Scottish Executive.

I would be very grateful if you could take the time to read the enclosed information leaflet and return the response slip if you would like to take part in my study.

Thank you for your time in reading this letter and the information leaflet.

I look forward to hearing from you.

Heather Milne

Appendix III: Patient information sheet

College of Humanities and Social Sciences

Patient Information Sheet

Experiences of Diabetes Services in Scottish Primary Care

I would like to invite you to take part in a study investigating patients' and health professionals experiences of diabetes care in general practices in differing locations across NHS Highland and NHS Grampian. Before you decide whether to take part it is important that you understand what the research is about and what will be involved in taking part. Please take the time to read the following information carefully and discuss it with others if you wish. Please contact me to ask if there is anything that is not clear or if you would like more information. Please take some time to decide whether you would like to take part. If you decide that would like to take part please return the enclosed response slip in the stamped, addressed envelope provided.

Thank you for reading this.

What is the purpose of this study?

The way that health care for type 2 diabetes is provided across Scotland has changed over the past four years. This research is to find out how; if at all, these changes have affected patients and the health professionals who provide services for type 2 diabetes.

This research will be used to help understand the ways in which health policy affects the health care that people actually receive, and whether the changes in the past few years have improved diabetes care. The results of the research will be sent to the Scottish Executive to help inform future improvements in diabetes care.

The research may also, be used to help design relevant questions for a survey instrument to find out what patients across Scotland think about the diabetes care provided by their general practice. This research is funded by the Scottish Executive and will be the basis for my PhD at the University of Edinburgh.

Why you have been chosen and what will be involved in taking part.

Taking part will involve an interview about your experiences of receiving health care for type 2 diabetes. This will last about 1 hour depending on how much you want to say. You can choose the time and place for your interview. I will ask if I can record the interview but, you can choose not to be recorded and I will write notes instead.

32 people who have had type 2 diabetes for at least 5 years and are registered at one of **4** general practices in two Heath Boards will be interviewed. I will also be carrying out interviews with health professionals at these practices about how they organise care for type 2 diabetes.

In the interview, I will ask you to tell me what the care you have received for your diabetes in general practice has been like. For example;

- How has your diabetes affected your life in general?
- What care have you received for your diabetes since you were diagnosed and from whom?
- Have you always had the same person looking after you and your diabetes?
- Have you had lots of different health professionals looking after you?
- Do you have one person that you turn to if you are worried about your diabetes?

At the end of the interview, you will be asked if they would mind being contacted one more time by telephone if I have any questions about the interview that need clarification. You may also choose to take part in the study but not to be contacted again following the initial interview.

I will also ask if you would be willing to give me feedback on my initial analysis of diabetes care in your area, you will be forwarded a copy of this by e-mail or post a few months after your interview

Anything said during **the interview is confidential** and any quotes I might use when I write about the project will be completely anonymous. Everyone who chooses to take part will be identified using a code number in order to ensure complete anonymity. Any quotes which may be taken from the interview, will be completely anonymous. You will be given a pseudonym in any publications and all place names and other identifying features will be changed.

I am interested in what you think is important in diabetes care, you do not have to answer any questions that make you feel uncomfortable, and you should feel free to raise issues you feel I may have overlooked.

At the end of the study, you will receive a summary of the findings and a report of how these are being used to improve diabetes care.

Do you have to take part?

Taking part is completely voluntary. If you choose to take part, **you can withdraw at any time without giving a reason** by just letting me know through a phone call, e-mail or letter. Whether you choose to take part or not will have no affect on the health care that you receive. Neither your GP nor any other medical staff will be told whether you choose to take part or not.

How to get involved.

If you would like to take part, please complete and return the attached response slip in the stamped addressed envelope, by the date on that form. This is not an agreement to take part in the research, but enables me to contact you to discuss any questions you may have and arrange an interview.

These letters were sent out on my behalf by your general practice. I do not have access to your address or contact details so if you would like to take part please include how I can contact you **e.g. a phone number, address or e-mail, so that we can arrange a time and place for your interview.**

At the time of the first interview I will discuss the project with you and ask you to sign a consent form. On this form, you will be able to choose whether you are willing to be tape recorded during the interview. You will also be able to choose whether or not the information from your interview could be used to inform a survey instrument in a possible future study. You will be given a copy of this form to keep. Consent is needed for any research in the NHS. The form will state that you have understood this information sheet and protects your rights to withdraw from the research at any time. If at any point during the study you would to make a complaint this will be addressed by my supervisors at the University of Edinburgh whose contact details are provided below.

Please keep this information sheet incase you have any further questions. If you have any questions please do not hesitate to phone me on 0131 651 3205, or e-mail: H.Milne-2@sms.ed.ac.uk **or write to me at the address at the top of this letter.**

Thank you very much for your time in reading this.

Heather Milne

Principal Supervisor: Dr. Andrew Thompson, Adam Ferguson Building, George Square, Edinburgh
Tel: 0131 651 3205

Appendix IV: Practice Staff information sheet

College of Humanities and Social Sciences

General Practice Staff Information Sheet

Experiences of diabetes services in Scottish Primary care

I am currently carrying out research into the factors affecting patients' and health professionals' experiences of receiving and providing diabetes care in 6 general practices in Highland and Grampian. The research involves non- participant observation in the general practices involved and interviews with patients, health professionals and practice staff involved in the daily organisation of diabetes care. **Your practice has agreed to take part in this study and you may be included in observations and/or invited to be interviewed**. **It is important that you read the following information and decide whether you would like to opt- out of my observations and/ or whether you would be willing to be interviewed**. Please take some time to read this information and discuss it with others if you wish. Please do not hesitate to contact me if you have any questions concerning the study.

Background to the research

This research aims to explore the impact of health policy on the organisation of primary care and the provision of diabetes services on a daily basis from the perspective of the health professionals and practice staff involved and the patients receiving care. In order to understand how health policy affects patients' experiences of receiving care for type 2 diabetes, their experiences will be placed alongside their health professionals' experiences of providing diabetes services.

The research will reflect on how health policies, such as the introduction of "QOF" points associated with new GMS contract, have affected the day to day provision of care for type 2 diabetes, and how different practices go about organising the care they provide. The research aims to highlight some of the barriers and facilitators to providing care for type 2 diabetes in differing primary care settings across Scotland. In addition, the research may be used to inform the design of a future survey instrument for use by practitioners to assess patients' experiences of receiving care for diabetes in their practice and allow for comparisons to be made on a national scale.

What is non- participant observation and how will it affect you?

In order to understand the context of the experiences of diabetes care and to inform the topic guides used in interviews, I will be carrying out some observation within your practice. The primary aim of the observation is to inform topics pursued in individual interviews so that they remain relevant to the organisational variations between practices. Observation will highlight variations in the way the members of the diabetes care team involved with different practices work together on a daily basis and how they go about coordinating care. **I intend to carry out participant observation in the practice on a daily basis for two weeks. This will involve being in and around the practice talking informally with the staff and observing how care is organised on a day-to-day basis. I will take notes about the day-to-day running of the practice and this will inform the topics later pursued in interviews. <u>These notes will be confidential and anonymous.</u>**

If you <u>do not</u> wish to be included in my observations please let the me know as soon as possible. If you choose to opt out of observations, I will exclude you from my field notes. Taking part is completely voluntary and if you choose to be involved in the observation you may withdraw at any time without giving a reason.

Interviews

I will also be carrying out individual in-depth interviews with all the various health professionals involved in providing diabetes care through the practice. I would also like to interview the members of the administrative team at each practice who are key to the organization and provision of diabetes care. The interview will take the form of an open ended discussion around your experiences of organizing care for diabetes, and how that has been affected by the nGMS contract.

If you are willing to be interviewed please, opt-in to this aspect of the research by returning the attached response slip in the envelope provided, I will then provide you with more information before arranging a time and place to interview you.

Anything said during **the interview is confidential** and any quotes I might use when I write about the project will be completely anonymous. **Everyone who chooses to take part will be identified using a code number in order to ensure complete anonymity**.

Being interviewed is completely voluntary and **you can withdraw at any time without giving a reason** by just letting me know in person or through a phone call, e-mail or letter. Whether you choose to take part or not will have no affect on your employment. **Thank you for your time in reading this. If you have any questions please do not hesitate to speak to me in person or phone me on 0131 651 3205, or e-mail:** H.Milne-2@sms.ed.ac.uk **.**

Appendix V: Consent form

COLLEGE of HUMANITIES and SOCIAL SCIENCE

RESEARCH PARTICPANT CONSENT FORM

Project: Experiences of diabetes services in Scottish Primary Care

Researcher: Heather Milne.

1. I confirm that I have read and understood the information sheet dated… For the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason and without my medical care and legal rights being affected.
3. I am willing to be audio-recorded during the interview.
4. I am willing for the information gained from this interview to be used to inform the development of a survey instrument to be used in future research.
5. The researcher may contact me once by telephone following this interview.
6. I agree to take part in the above study.

Name of Patient: Signature:

Researcher: Signature:

(1 copy to participant; 1 copy to researcher.)

Appendix VI: Patient Response Slip

COLLEGE of HUMANITIES and SOCIAL SCIENCE

Patient Response Slip

Experiences of diabetes services in Scottish Primary care

Please return this form by ……..

NB: signing this form does not commit you to taking part in this research.

I, (please print your name) am interested in this study and am willing to be contacted by Heather Milne.

Signed:

Address:……
……
……
…

E-mail:……..

Telephone number:…….

Please indicate a suitable time to contact you to discuss the study and arrange an interview.

Sex	Age	Length of time since diagnosed with type 2 diabetes (approx)
Male / Female	18- 30 31- 40 41-50 51-60 61- 70 71-80 80 +	5-10 yrs 11- 15yrs 16-20yrs 21-25yrs 26-30yrs 31-35yrs 36yrs +

Thank you for your interest in the research I will be in touch shortly.

Heather Milne.

Appendix VII: Staff and Health Professional Response Slip

COLLEGE of HUMANITIES and SOCIAL SCIENCE

Health Professional Response Slip

Experiences of diabetes services in Scottish Primary care

Please return this form by ……..

NB: signing this form does not commit you to taking part in this research.

I, (please print your name) am interested in this study and am willing to be contacted by Heather Milne.

Please tick the box if you DO NOT want to be included in my observations at your general practice. ☐

Signed:

Occupation:……

Address:……

……

……

…

E-mail:……..

Telephone number:…….

Please indicate a suitable time to contact you to discuss the study and arrange an interview……

Thank you for your interest in the research I will be in touch shortly.

Heather Milne

Appendix VIII: Patient Interview Topic Guide

Topic guide for in-depth interviews with patients

The interview will focus on two main topics: the experience of living with type 2 diabetes; the experience of receiving care for type 2 diabetes in primary care. However, the topics may not be covered in the order outlined below.

START: Personal Introduction and explanation of the research, address any questions, explain consent form.

PART 1: **Experience of living with type 2 diabetes**

1. How did they find out that they had the condition?
   How long since they were diagnosed with diabetes?
   Perceived severity of condition past and present.
2. What was their initial response to the diagnosis.

How has life with their diabetes changed over the years and why? The story of their time with diabetes.

3. How they learnt about diabetes and self-care.
4. Manner in which diabetes has been managed over the years and why there have been any changes. (diet/exercise/ hypoglycaemics/ insulin)

PART 2: Experience of receiving care for type 2 diabetes in primary care

1. Which health professionals (and where) they have consulted about their diabetes over the course of the years?
   Which and how many clinicians are involved, is this important? (same advice, coherent, caring)
2. When did they last saw someone about their diabetes.
   Who arranged the consultation and why.
   Description of the consultation.

3. How frequently do they see someone for their diabetes?

4. What test and measurements were taken?

   What are these for, why are they taken?

5. Do they feel involved in planning your diabetes management? Do they want to be?

TOWARDS END OF INTERVIEW

1. If anything what would they like to see improved in their diabetes care?
2. If anything are their important concerns with their diabetes or its care which they feel we have not yet discussed, or which they feel I should be investigating.

To be covered towards end of interview:

- Age
- Length of time since diagnosis
- Employment/ previous employment / partners employment
- How long have been registered at the general practice under study

END WITH THANKS, A SUMMARY AND LIGHTER CONVERSATION, INVITE FURTHER QUESTIONS.

Appendix IX: Professional Interview Topic Guide

Topic guide for in-depth interviews with health professionals

The interview will focus on two main topics: the organisation of diabetes care in the primary care team; providing care.

START: Personal Introduction and explanation of the research, address any questions, explain consent form.

PART 1: The organisation of diabetes care in the primary care team

1. Role in diabetes care in the practice?
    a. Organisation of diabetes care at practice e.g. other professionals involved.
2. Is primary care the appropriate place for diabetes care?
3. What are the pros and cons of providing diabetes care in your particular practice?
4. How a patient might progress from one health professional to another. How referrals happen.
5. Personal experience of diabetes and learning how to manage diabetes.
6. What has the GMS, SDF and MCN meant for the way in which you provide diabetes care?
7. What source of knowledge they turn to when they have a question or are not sure of the correct way to treat a particular problem in a patient with type 2 diabetes.
    a. How do you use the SIGN guidelines in everyday practice.

PART 2: Providing care. (continuity of care and holistic approach of general practice)

1. Do patients with type 2 diabetes always see the same people for their diabetes care? Is that important?
2. Do you feel you know the patients you see with type 2 diabetes…is that important?
3. What education/ information do you provide?
4. How do you involve patients in clinical decisions? How do you go about deciding on the correct regimen for each patient?
5. Would you say that some of your patients are more "empowered" to take care of their diabetes than others? What does this mean?

TOWARDS END OF INTERVIEW

1. If anything what would they like to see improved in diabetes care in this locality?
2. Are their important concerns with their diabetes care which they feel we have not yet discussed, or which they feel I should be investigating.

- **Demographic aspects to be covered towards end of interview:**
    - Age
    - Length of time been qualified
    - Length of time working at the practice

END WITH THANKS, A SUMMARY AND LIGHTER CONVERSATION, INVITE FURTHER QUESTIONS.

Appendix X: Scottish Executive Urban/Rural Classification 2003-2004. (ISD Scotland, 2006b)

	Scottish Executive Urban Rural Classification
1	Large Urban Areas Settlements of over 125,000 people.
2	Other Urban Areas Settlements of 10,000 to 125,000 people.
3	Accessible Small Towns Settlements of between 3,000 and 10,000 people and within 30 minutes drive of a settlement of 10,000 or more.
4	Remote Small Towns Settlements of between 3,000 and 10,000 people and with a drive time of between 30 and 60 minutes to a settlement of 10,000 or more.
5	Very Remote Small Towns Settlements of between 3,000 and 10,000 people and with a drive time of over 60 minutes to a settlement of 10,000 or more.
6	Accessible Rural Settlements of less than 3,000 people and within 30 minutes drive of a settlement of 10,000 or more
7	Remote Rural Settlements of less than 3,000 people and with a drive time of between 30 and 60 minutes to a settlement of 10,000 or more.
8	Very Remote Rural Settlements of less than 3,000 people and with a drive time of over 60 minutes to a settlement of 10,000 or more